The Swedish Maternal Health Care Register: Internal Validity, User Perspectives and Register Outcomes; and Experiences by Midwives in Antenatal Care

Kerstin Petersson

Department of Clinical Sciences
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Umeå University
901 87 Umeå
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Margareta Hammarström in memoriam

Mellanrum, leva i mellanrummen
mellan
Tid
Krypa ut, hitta sprickor, hålrum och längtan
Det spelar väl ingen roll och ändå betyder det allt

Anna Leijonhielm

*

Objective is to get a valid and precise estimate of
the effect of an exposure on an outcome

Matthew Fox

Med fantasin mot blinda fläcken

Per Naroskin

Allvar muntrar upp

Maria Leijonhielm

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PAPER I-IV

ABSTRACT

Background

The Swedish Maternal Health Care Register (MHCR) is a national quality register used within antenatal care (ANC) services to assess quality of provided care, quality improvement of ANC as well as for research purposes. Established in 1999, the MHCR collects data on pregnant women and their offspring related to pregnancy, delivery and postpartum. Since 2013 MHCR is included in the Swedish Pregnancy Register (SPR), which consists of three different parts, the Maternal Health Care Register, the Swedish National Quality Register for Prenatal Diagnosis, and the Obstetric Register. Midwives in ANC register data manually in the web-application designed for MHCR on two occasions, after the pregnant woman's first visit in ANC and postpartum. Midwives in ANC are responsible for providing information to expecting parents about prenatal diagnosis however the actual procedures are generally undertaken in hospital-based clinics. In the Swedish setting, prenatal diagnosis currently includes a second trimester scan usually performed at a gestational age of 17 to 20 weeks, combined ultrasound and biochemical test (CUB) and invasive tests such as chorionic villus sampling (CVS) or amniocentesis (AC). Almost all pregnant women attend ANC in Sweden. The majority of the antenatal care services operates within the public primary health care system. Midwives are the primary providers of health care during pregnancy, independently responsible for surveillance of uncomplicated pregnancies. Additional assignments for midwives in ANC are parental support, family planning and prescription of contraceptives, performing the national, population-based screening programme for cervical cancer and public outreach work. Midwives also manage different patient-related administrative systems.

Aims

The overall aims for this thesis were to investigate different aspects of the Swedish Maternal Health Care Register (MHCR) in regard to validity of register data, user experience, opinions and use of the register, and register outcomes data. Additional aims were to investigate structural and organisational factors affecting the midwives' work situation in antenatal care and their experiences of informing expectant parents about prenatal diagnosis.

Methods

Study I, II and III were cross-sectional studies. Study I compared pregnancy and delivery data in medical records with corresponding data in the Maternal Health Care Register on 978 pregnant women for 2011. Study II was a questionnaire survey performed January 2012 to March 2012 that addressed all midwives in Swedish ANC (N=989). Study III analysed data on pregnancies retrieved from the Swedish Maternal Health Care Register and the Swedish Pregnancy Register comprising 284,789 women and their offspring 2011-2013. Different statistical analyses were performed in Study I, II, and III, Cohens Kappa, Pearson's Chi-Square test, sensitivity and specificity, and univariate and multivariable logistic regression analyses. Study IV, a qualitative study collected data using individual telephone interviews with 15 midwives currently working in different ANC settings. Qualitative content analysis was applied in analysis.

Main findings

Overall, the degree of coverage of variables was high in the Swedish Maternal Health Care Register as well as in the medical records. The variables with a relatively lower degree of coverage in the MHCR addressed various forms of prenatal diagnosis with a degree of coverage of approximately 90%. Identical data in both data sources ranged from 73.9% to 99.7%. For 17 of the 27 variables, agreement of data in both data sources reached 95% or more. Variables with the highest frequencies of identical information in the MHCR and in the medical records were mainly data related to delivery, such as "singleton birth/multiple births", "live born child", and "gender of child". Possible systematic errors were identified for two variables, i.e. "second trimester serum screening" and "number of ANC visits". Midwives valued positively the web-application used for MHCR although manual registration of data into the register was perceived as burdensome by a majority of the midwives performing patient-related work tasks exclusively (70.7%). The variables in the MHCR were generally valued relevant. However, some variables were perceived as redundant, e.g. variables on prenatal diagnosis, whereas other variables were requested, e.g. inter-current diseases during pregnancy and medical complications during pregnancy and birth. Midwives engaged in supervision demonstrated an increased likelihood to regularly accessing data on pregnant women at their own ANC clinic, ($p<0.001$; OR=11.79 CI 95% 7.43-18.69), and a decreased likelihood to question the benefit of the register ($p<0.001$; OR=0.29 CI 95% 0.16-0.49) in comparison with midwives with patient-related work tasks exclusively. Offers on prenatal diagnosis varied considerably between the 21 Swedish counties during 2011-2013. Six counties offered CUB test to

all pregnant women, nine counties at specific indications, and five counties did not offer CUB at all. One county did not have any written guidelines. During the same period, the national uptake of routine ultrasound examination, CUB, AC and CVS were, 97.6%, 33.0%, 2.6% and 1.1%, respectively. Advanced maternal age demonstrated the highest impact on uptake of prenatal diagnosis. University educational level in relation to lower educational level was associated with an increased likelihood of undergoing CUB (OR 2.30, 95% CI 2.26-2.35), AC (OR 1.54, 95% CI 1.46-1.63) and CVS (OR 2.68, 95% CI 2.44-2.93). Midwives in ANC reported their work load to be manageable, although high. Clinical guidelines, continuing education, and collaboration between health professionals in the chain of care of the pregnant woman, were experienced underpinning the work. Administrative work load was perceived as strenuous. Informing expecting parents about prenatal diagnosis was experienced as challenging.

Conclusions

Data in the Swedish Maternal Health Care Register demonstrated good to very good degree of coverage, agreement, and internal validity for most variables. MHCR was generally valued positively by midwives. However, the work task on registration of data in MHCR was perceived as burdensome. Offers on prenatal diagnosis varied in different counties in Sweden. Maternal age and educational level demonstrated the highest impact on uptake of prenatal diagnosis. Midwives enjoyed their work in ANC although administrative work tasks were strenuous. Informing expecting parents about prenatal diagnosis was challenging. The register has a potential to further develop its on-line report system to be used to a higher extent in evaluation and planning of Swedish maternal health care services. Expecting couples in Sweden should be offered the same opportunities on prenatal diagnosis, and pedagogical tools may facilitate midwives mission to inform expecting parents with varying pre-understanding about prenatal diagnosis.

Key words

Quality registers, medical records, validity, degree of coverage, antenatal care, pregnancy, prenatal diagnosis, uptake, work condition, guidelines, epidemiology, qualitative research

SAMMANFATTNING

Bakgrund

Det svenska Mödrahälsovårdsregistret är ett nationellt kvalitetsregister som används inom mödrahälsovården för uppföljning av verksamheten, i förbättringsarbete och som underlag för forskning. Mödrahälsovårdsregistret startade 1999 och samlar in data på gravida kvinnor, förlossningar och nyfödda barn. Sedan 2013 är Mödrahälsovårdsregistret en del av Graviditetsregistret, som består av tre delregister; Mödrahälsovårdsregistret, Fosterdiagnostikregistret och det Obstetriska registret. Barnmorskor inom svensk mödrahälsovård registrerar data manuellt vid två tillfällen i registret, dels i anslutning till inskrivningsbesöket, och dels efter avslutad graviditet, senast 16 veckor efter förlossningen. Barnmorskor inom svensk mödrahälsovård har skyldighet att erbjuda blivande föräldrar information om fosterdiagnostik. Däremot utförs de fosterdiagnostiska undersökningarna på särskilda mottagningar, vanligen inom ramen för Sveriges kvinnokliniker. Med tidig fosterdiagnostik avses rutinultraljud i graviditetsvecka 17 till 20, kombinerat ultraljud och biokemiskt test (KUB), samt de invasiva undersökningarna fostervattenprov (AC) och korionvillibiopsi (CVS). Nästan alla gravida kvinnor kontrolleras inom mödrahälsovården. Majoriteten av mödrahälsovårdsmottagningarna bedrivs inom den offentliga primärvården. Barnmorskan arbetar självständigt och är ansvarig för kvinnor med okomplicerade graviditeter. Övriga uppdrag för barnmorskor inom svensk mödrahälsovård är, föräldrastödsverksamhet, rådgivning och förskrivning av preventivmedel, screening för livmoderhalscancer, samt utåtriktat arbete. I barnmorskans arbete ingår därutöver olika patientadministrativa uppgifter.

Syfte

Det övergripande syftet med avhandlingen var att undersöka det svenska Mödrahälsovårdsregistret ur följande aspekter: intern validitet i registerdata, användarnas erfarenheter, synpunkter och användning av registret samt registerutfall. Ytterligare syften var att undersöka stödjande och belastande faktorer för barnmorskans arbetssituation inom svensk mödrahälsovård och barnmorskors erfarenheter och synpunkter av att informera blivande föräldrar om fosterdiagnostik.

Metod

Studie I, II och III var tvärsnittsstudier. I Studie I jämfördes data i den medicinska journalen med motsvarande uppgifter i Mödrahälsovårds-registret över 879 gravida kvinnor med ett förlossningsdatum under maj till juni 2011. Studie II var en enkätundersökning som riktade sig till samtliga barnmorskor inom svensk mödrahälsovård (N=989). Undersökningen genomfördes januari till mars 2012. I Studie III analyserades data på totalt 284,789 gravida kvinnor och deras nyfödda barn under perioden 2011 till 2013. Statistiska analyser som användes i Studie I, II och III var Cohen's Kappa, Pearson's Chi-två test, sensitivitet och specificitet, samt univariat och multivariat logistisk regressionsanalys. Studie IV var en kvalitativ studie där data insamlades vid individuella telefonintervjuer med totalt 15 barnmorskor verksamma vid olika mödrahälsovårdsmottagningar. Materialet analyserades med kvalitativ innehållsanalys.

Resultat

Variablerna uppvisade överlag en hög täckningsgrad i både Mödrahälso-vårdsregistret och den medicinska journalen. Variabler gällande fosterdiagnostik uppvisade en något lägre täckningsgrad på cirka 90 %. Andelen identiska data i de båda datakällorna varierade från 73,9 % till 99,7 %. För 17 av de 27 undersökta variablerna var överensstämmelsen mellan de båda datakällorna, 95 % eller högre. Variabler relaterade till förlossningen (”enkelbörd/flerbörd”, ”levande fött barn”, och ”barnets kön”) var de variabler som uppvisade högst andel identiska uppgifter i de båda datakällorna. Systematiska fel identifierades för två variabler, ”andra trimester serum screening”, och ”antal barnmorskebesök”. Barnmorskor var överlag positiva till Mödrahälsovårdsregistrets webbapplikation, däremot upplevde en majoritet (70,7 %) av barnmorskorna med enbart patientarbete att den manuella registreringen var en betungande arbetsuppgift. Mödrahälsovårdsregistrets ingående variabler uppfattades som relevanta. I fritext frågorna kommenterades att en del variabler var onödiga, till exempel frågor om fosterdiagnostik medan andra variabler saknades i registret, exempelvis frågor om sjukdomar och medicinska komplikationer under graviditet och förlossning. Barnmorskor med arbetsledande uppgifter rapporterade i jämförelse med de barnmorskor som enbart hade patientarbete att de i högre utsträckning regelbundet extraherade data från registret avseende den egna mottagningen ($p<0,001$; OR=11,79 CI 95 % 7,43-18,69), och de uppvisade en minskad sannolikhet att ifrågasätta nyttan med registret ($p<0,001$; OR=0,29 CI 95 % 0,16-0,49). Erbjudande om fosterdiagnostik till blivande föräldrar varierade betydligt mellan de 21 landstingen under åren 2011-2013. Sex landsting erbjöd KUB till alla gravida

kvinnor, nio landsting erbjöd KUB på indikation och fem landsting erbjöd inte KUB till gravida kvinnor. Ett landsting hade inga skrivna riktlinjer. Under samma tidsperiod var andelen kvinnor som genomgick ultraljud i graviditetsvecka 17-20, 97,6 %, KUB 33,0 %, AC 2,6 % och CVS 1,1 %. Moderns ålder uppvisade störst inverkan på genom-gången fosterdiagnostik. Utbildningsnivå universitet i jämförelse med lägre utbildningsnivå var associerad med en ökad sannolikhet att genomgå KUB (OR 2,30, 95 % CI 2,26-2,35), AC (OR 1,54, 95 % CI 1,46-1,63) och CVS (OR 2,68, 95 % CI 2,44-2,93). Barnmorskor inom svensk mödrahälsovård ansåg att arbetsbelastningen var hanterbar även om den var hög. Kliniska riktlinjer, regelbunden fortbildning, och samarbetet med kollegor och läkare i vårdkedjan för den gravida kvinnan beskrevs som stödjande faktorer i arbete. Den administrativa arbetsbelastningen upplevdes som krävande och att informera blivande föräldrar om fosterdiagnostik som utmanande.

Slutsats

Data i Mödrahälsovårdsregistret uppvisade god till mycket god täcknings-grad, överensstämmelse och intern validitet för de flesta variablerna i registret. Barnmorskor var överlag positiva till Mödrahälsovårdsregistret, även om arbetsuppgiften att föra in uppgifter manuellt i registret upplevdes som betungande. Erbjudande om fosterdiagnostik varierade avsevärt mellan olika landsting. Moderns ålder och utbildningsnivå var de faktorer som uppvisade störst inverkan på genomgången fosterdiagnostik. Barnmorskor uppskattade sitt arbete inom mödrahälsovården, men det administrativa arbetet upplevdes som krävande. Att informera blivande föräldrar om fosterdiagnostik upplevdes som utmanande. Mödrahälsovårdsregistret har en utvecklingspotential vad gäller dess rapportfunktioner och registerdata skulle i högre grad kunna användas i planering och förbättring av innehållet i svensk mödrahälsovård. Erbjudande om fosterdiagnostik till blivande föräldrar borde vara likvärdiga i samtliga landsting i Sverige. Pedagogiska hjälpmedel skulle kunna underlätta för barnmorskor att informera blivande föräldrar med olika kunskapsnivå vad gäller fosterdiagnostik.

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I. **Petersson K**, Persson M, Lindkvist M, Hammarström M, Nilses C, Haglund I, Skogsdal Y, Mogren I.
Internal validity of the Swedish Maternal Health Care Register. *BMC Health Services Research.* 2014 August 30; 14:364

II. **Petersson K**, Persson M, Lindkvist M, Hammarström M, Haglund I, Nilses C, Skogsdal Y, Mogren I.
User Perspectives on the Swedish Maternal Health Care Register. *BMC Health Services Research.* 2014 December 10; 14:613

III. **Petersson K**, Lindkvist M, Persson M, Conner P, Åhman A, Mogren I.
Prenatal diagnosis in Sweden 2011 to 2013 – a register-based study. Submitted.

IV. **Petersson K**, Persson M, Mogren I.
"The computer deprives me of my time with patients" – Swedish midwives' experiences in antenatal care. Submitted.

ABBREVIATIONS

AC	Amniocentesis
ACC	Antenatal Care Coordinator (midwife)
ACO	Antenatal Care Obstetrician
ANC	Antenatal Care
AOR	Adjusted Odds Ratio
AUDIT	Alcohol Use Disorder Identification Test
BMI	Body Mass Index
CI	Confidence Interval
COR	Crude Odds Ratio
CS	Caesarean Section
CUB	Combined Ultrasound and Biochemical Test
CVS	Chorionic Villus Sampling
IPV	Intimate Partner Violence
IQR	Inter Quartile Range
MBR	Medical Birth Register
MHCA	Maternal Health Care Area
MHCR	The Maternal Health Care Register
NBHW	The National Board of Health and Welfare
OGTT	Oral Glucose Tolerance Test
OR	Odds Ratio
QCA	Qualitative Content Analysis
SPR	The Swedish Pregnancy Register
UCR	Uppsala Clinical Research Center
WHO	World Health Organization

DEFINITIONS AND GLOSSARY

ANC-team	In Sweden, each department or primary care unit has an obstetrician, and a midwife, in this thesis termed antenatal consultant obstetrician (ACO) and antenatal care coordinator (ACC). They are responsible for medical policy, quality issues, continuing education of antenatal care physicians and midwives and clinical guidelines, statistics and follow-up. In paper II, other terms i.e. senior consultant obstetrician and senior consultant midwife has been used for the same professional functions.
BMI	Body Mass Index (kg/m^2).
Confidence Interval	The estimated interval that includes the true value of a variable such as mean, proportion or rate, to a specified grade of confidence (e.g. 95%).
Cross sectional	A study examining the relationship between a disease and other relevant variables in a specified population at a specified time.
Inductive Content analysis	A qualitative method of content analysis to develop theory and identify themes emerging from the data through repeated examination and comparison. An inductive method is used when there is limited or no knowledge on the phenomenon.
IQR	Inter Quartile Range, a measure of variability, based on dividing a data set into quartiles.
Logistic regression	Measures the relationship between a categorical dependent variable and one or more independent variables estimating probabilities.
Odds Ratio	The ratio between two odds. Odds ratio is a calculation of the odds of exposure among cases divided by the odds of exposure among controls.
Opt-out	In this thesis the term opt-out refers to a person's possibility to decline to contribute with her personal data to a register, or to have data deleted from a register.
Power estimation	An estimation of the sample size needed to reject the null hypothesis when it is false.

Prenatal diagnosis	In this thesis prenatal diagnosis includes screening or diagnostic procedures up to 22 weeks of gestation to detect any fetal abnormality.
Qualitative content analysis	A systematic, step by step analysis of a text. The core feature of QCA is to condense a text, create categories and identify a theme.
Sensitivity	A measure of the likelihood that a test correctly identifies a condition/disease. E.g.; the number of test positive persons divided by the true number of persons with a disease.
Specificity	A measure of the likelihood that a test correctly identifies the absence of a condition/disease. E.g.; the number of test negative persons divided by the true number of negative persons.
Semi-structured interview	An interview guide is used during the formal interview. The guide consists of a number of questions or topics that need to be covered. The interviewer may leave the guide and follow new emerging ideas and unexpected information from the participants.

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INTRODUCTION

Register

Population-Based Registers

The term register relates to data that are collected in a structured manner or data that are systematically organised. A register can include either an entire population within a geographical area (i.e., population-based) or a selected defined population (1). In Sweden, two registers include the total Swedish population: the Population Register, administered by the Swedish National Tax Agency, and the Total Population Register (TPR), managed by the government agency Statistics Sweden. The quality and coverage of data in these registers are regarded as high. The TPR includes data on birth, death, marriage, change of name, change of sex, and place of residence (2). Since 1947, every person born in Sweden or residing in Sweden on a permanent basis is given a ten-digit unique personal identity number (3). The personal identity number enables the linkage of different registers and is an essential key variable in register-based research within health care in Sweden (3).

Health Data Registers and National Quality Registers in Health Care

Principally, Swedish health care uses two types of national registers that include information on health outcomes, i.e. health data registers and national quality registers. The health data registers are regulated by the Health Data Law (4) and the quality registers by the Patient Data Law (5). The Swedish National Board of Health and Welfare (NBHW) manages the health data registers, and it is mandatory for health care services as well as for individual patients to contribute their data to these registers (5). The NBHW administers health data registers i.e. the Cancer Register, the Cause of Death Register, the National Patient Register, and the Medical Birth Register. The NBHW also manages registers on prescriptions on drugs, dental health, and municipal interventions in public health care. In the 1960s, measuring health care in terms of structures, processes, and outcomes was introduced (6). During the 1970s and the 1980s, quality assurance in health care was discussed in international as well as in Swedish publications and documents (7). Today, all health care providers in Sweden are obliged to operate systematic self-monitoring systems with possibilities to compare different outcomes on regional and national levels as well as changes over time (5, 8). In Sweden, the first quality register, i.e. the Swedish Knee Arthroplasty Register, started in 1975 and surveys health outcomes. This initiative was followed by other orthopaedic quality registers (7). Over the last several decades, professional associations in different medical areas have initiated and administered national quality registers that include

individualised data on medical diagnosis, processes, interventions, and health outcomes. The main purpose of quality registers are to be used in quality assessment and improvement in health care, as well as in continuous learning within health care. Another significant purpose for quality registers are to be used in research (9). The quality registers usually generate real-time data that are accessible on-line for involved health care providers (9). Currently, Sweden has 96 national quality registers in varying fields of medicine (7, 9). Unlike health data registers, participation in quality registers is not mandatory – i.e., patients are not obligated to provide data to quality registers. Health care providers are legally obligated to inform patients on the purpose of the specific quality register and the voluntary nature of participation for the individual patient (5). The quality registers are annually monitored and approved for funding by public health authorities and the government (9).

Registers operating within reproductive health care

The Swedish Medical Birth Register

The Nordic countries have a long tradition of population-based health data registers that collect data on pregnancies and childbirths. In Norway, a Medical Birth Register was established in 1967, followed by Denmark in 1968, Iceland in 1972, Sweden in 1973, and Finland in 1987. Since 1982, the Swedish Medical Birth Register (MBR) has collected data from medical records used in antenatal and maternal health care (10). Since its inception, the MBR has been used in a wide variety of areas within pregnancy and childbirth research (11-16).

The Swedish Maternal Health Care Register and the Swedish Pregnancy Register

In the 1990s, the National Board of Health and Welfare and a group of antenatal care obstetricians (ACO) and antenatal care coordinators (ACC), who are midwives, agreed on a number of quality indicators to be used for assessment of the quality of ANC services. The Swedish Maternal Health Care Register (MHCR) was established in 1999, with the quality indicators as a foundation for collection of national data on pregnancies and new-borns (personal message). Since the start of the register, a national report has been published annually on individual data as well as data on structure and organisation of ANC. The annual reports are published on the Swedish Pregnancy Register (SPR) webpage (https://www.graviditetsregistret.se) (17). Over the years, all Swedish counties and almost all ANC clinics have participated in the MHCR. In 2013, the coverage of individual data was estimated to 89% (17). Until 2012, the MHCR acted as an autonomous quality register for 14 years. Uppsala Clinical Research Center (UCR) managed the database as well as the web-application used for registration and extraction of

data in MHCR between 2010 and 2015. All variables included were then registered manually by ANC midwives on two occasions, i.e. at early pregnancy after the first ANC visit and after completed pregnancy (i.e. postpartum). At the time, the Swedish Society of Obstetrics and Gynecology and the Swedish Association of Midwives requested a quality register that not only surveyed antenatal care in primary health care but also surveyed hospital-based maternal health care. Later, the advantage of only one comprehensive quality register in the chain of provision of health care to pregnant women was emphasised. These discussions resulted in the Swedish Pregnancy Register (SPR) introduced in 2013. SPR actually merged three registers, i.e. the MHCR, the Swedish National Quality Register for Prenatal Diagnosis, which started in 2010, and the Obstetric Register, which started in 2014 (personal message). Midwives in antenatal care had previously requested an electronic direct transferral of data from the medical records to the MHCR to decrease the administrative work load (18). Introducing a new administrative work task for midwives in maternal care was not an option in 2013 (personal message). In 2014, the IT-systems were changed (e.g., database and web-application for the register). Currently, the majority of the included variables in the SPR are imported by electronic direct transferral of data from the medical records to the register. However, some data included in SPR are still registered manually by ANC midwives. These data include variables not registered in the medical record at all and variables that are not technically possible to transfer from the medical records. To increase the accuracy of data registration, the registrations are recommended to occur in close connection to the midwife's encounter with the pregnant woman (personal message). In 2007, the Quality Register on In Vitro Fertilization (QIVF) was established (19), and in 2014 the Swedish Vaginal Laceration Register was established (17). These two registers are currently not included in the SPR.

Midwifery education

During the 18th century, the first midwifery educational institute in Sweden was established (20). Today, midwifery is an academic discipline offered at 12 Swedish universities as specialist training for registered nurses. That is, all midwives educated in Sweden are also nurses (21). In addition, these midwives can prescribe contraceptives to healthy women (22).

Antenatal Care

A historical and global perspective

Inspired by the maternal health care services established in England, antenatal care (ANC) in Sweden began in the 1930s. Since 1938, ANC has been offered

free of charge to pregnant women in Sweden. Initially, only two ANC visits were included in the surveillance programme during a pregnancy: one visit with a midwife during early pregnancy and one visit with a doctor during late pregnancy (23, 24). Later, the medical surveillance during pregnancy included measurement of proteinuria on eight to ten occasions during a pregnancy to primarily detect preeclampsia. Provision of parental support has always been a part of the work tasks of midwives. Until the 1970s, parental support mainly focused on social aspects such as educating women in basic hygiene and how to take care of their new-born baby (23, 24). From the 1930s, antenatal care regulations became more extensive and detailed regarding the responsibilities of midwives. The status of a midwife in Sweden was enhanced through this ANC development. From being mostly considered as an assistant to the doctor, midwives became independently responsible for surveillance of uncomplicated pregnancies and uncomplicated childbirths (23). Furthermore, medical tests and examinations were included such as measuring blood pressure, hemoglobin level, and maternal weight during pregnancy. Later, tests for syphilis and gonorrhoea were also introduced. Rubella-serology, cervical cancer tests, and blood type tests were also included in the battery of surveillance tests. During the 1970s, an increasing interest was directed towards the fetal wellbeing and methods for assessment of fetal growth were developed using symphysis fundal height measurement (23). In Sweden, almost all pregnant women attend ANC (23). The maternal mortality ratio in Sweden is currently very low; between 1988 and 2013 the maternal mortality ratio was 6.0 per 100,000 live born children (25). Globally, approximately 830 women die every day from preventable causes related to pregnancy and childbirth, and 99% of these maternal deaths occur in developing countries. In the developing countries, the two major causes of maternal deaths are pre-eclampsia and eclampsia. Currently, the World Health Organization (WHO) recommends a minimum of four ANC visits during pregnancy. However, approximately 50% of all pregnant women globally do not receive the recommended number of ANC visits (26). Several intervention projects attempt to increase maternal health care utilisation (26, 27) such as the Mobile Health Intervention (28). A review study investigating pregnant women's requests related to ANC services concludes that a positive pregnancy experience is valuable for women despite cultural and socio-economic differences. To support such an experience, ANC should tailor health care services for the needs of individual women (29). Furthermore, ANC should pay more attention to promotion of health and wellbeing rather than solely being focused on identifying risks and treatment of pathology (29). As psychosocial factors seem to be of equal importance as physical factors for pregnant women, the WHO suggests that ANC include these aspects in their guidelines, not merely as principles but as interventions of the same dignity as clinical interventions (30).

Organisation of antenatal care in Sweden

In Sweden, the 21 county councils and regions are obliged to provide health care to their populations (31). During 2013, 48 hospitals in Sweden provided maternal health care services, and approximately 560 ANC clinics provided antenatal care (personal message). Since the beginning of the 1980s, antenatal care has been organised in defined Maternal Health Care Areas (MHCA), and these usually include all ANC in the geographical catchment area of a specified hospital. In each MHCA, an ANC team – an antenatal care obstetrician and an antenatal care coordinator (a midwife) – are responsible for evaluating and improving ANC quality, providing local clinical guidelines, and offering continuing education for ANC midwives and physicians. In general, the ANC teams represent the ANC in matters related to health care, locally and nationally. Every year, the ANC teams attend national conferences where they share and discuss relevant research, current quality improvement projects, and implementation of new guidelines (23). During 2013, 42 ANC teams operated in Sweden (17). ANC is primarily organised within the Swedish primary health care system (83.1%) and merely 15.6% is managed by hospitals (17). A majority of ANC operates in the public health care system subsequently only a minor part of ANC is a private enterprise. However, private ANC increased between 2010 (16.9%) and 2013 (23.8%) (17). During 2013, a majority of the ANC (83.6%) surveyed less than 400 registered pregnant women per year, whereas a majority of the pregnant women (50.3%) attended ANC with more than 400 registered pregnant women per year. This reflects Sweden's demography – large rural areas with low population density.

Antenatal care of today in Sweden

The overall aim for Swedish antenatal care is to promote good sexual and reproductive health for the entire population (23). Presently, the work assignments for midwives in antenatal care include *i)* surveillance of pregnancy, *ii)* parental support and preparation for childbirth, *iii)* individual contraceptive counselling, *iv)* prevention of sexually transmitted diseases (STI), *v)* public outreach work to prevent unplanned pregnancies and prevention of STI on a community level, *vi)* cervical cancer screening tests, and *vii)* counselling on lifestyle habits (23). There is currently no evidence on the optimal number of ANC visits during an uncomplicated pregnancy in order to ensure the medical safety for the pregnant woman and her fetus (32-34). In the Swedish national guidelines published in 2008, a minimum of eight visits during pregnancy is recommended. Additionally, a visit eight to twelve weeks postpartum should be offered as a part of the ANC programme (23). A detailed schedule including content and the recommended examinations at each visit is described in the local clinical guidelines for MHCA. The first antenatal interview is recommended to be divided into two visits. The first ANC visit should be

during early pregnancy and should focus on lifestyle habits as these habits have the potential to negatively or positively impact the wellbeing of the fetus as well as the pregnant woman. The second ANC visit should focus on medical, obstetric, and psychosocial factors (23). This strategy, however, emphasises an individual plan of care for each pregnant woman with regard to medical and psychosocial risk factors as well as taking into account the pregnant woman's own lifestyle habits and wishes (23). Identifying previous psychiatric history and/or current treatment for psychiatric disorder in early pregnancy also helps establish an individual plan of care for the pregnant woman (23, 35). Depressive illness is the major psychiatric diagnosis during pregnancy, and the prevalence during pregnancy has been estimated to be 10-15% (36). Pregnant women with a significant medical history of major depression face a 50% risk of recurrence during pregnancy and postpartum (35). The Edinburgh Postnatal Depression Scale (EPDS) is validated for use as a screening instrument during pregnancy (36, 37). However, the EPDS is mainly used on indication and not as a universal screening tool in Swedish antenatal care (17). During 2013, data in the Swedish Pregnancy Register estimates that 6.6% of the pregnant women received medical or psychological treatment for psychiatric disorder during pregnancy (17). A history of intimate partner violence (IPV) is associated with antenatal depression or anxiety (38). IPV during pregnancy puts two lives at risk and is associated with preterm birth and low birth weight (39). In antenatal care, universal screening for partner violence increases the clinical identification of pregnant women who have experienced IPV (40). Midwives are positive towards asking pregnant women about IPV exposure, although due to the routine of inviting the partner to each visit midwives may find it difficult to identify the proper moment to interview the pregnant woman about possible IPV (41). A majority of the pregnant women perceive that being questioned about IPV is acceptable (42) and during 2013 72.9% of the pregnant women in Sweden were interviewed by a midwife about IPV (17). There is a diversity in how parental education is organised in Swedish antenatal care (43), and the task to manage parental groups is experienced as a challenge by many midwives (44, 45). The SPR collects data annually on local guidelines on parental education as well as individual data on participation by the pregnant woman and her partner in parental education organised by the ANC. The SPR annual report shows that during 2013, 72.1% of primiparous women and 66.5% of their partners participated in parental education groups (17). Swedish midwives are licensed to prescribe contraceptives to healthy women (22) and ANC midwives and the Youth Health Centres are the main providers of counselling and prescription on contraceptives to fertile women, including insertion of intrauterine devices (46). During 2013, 43% of the ANC reported performing public outreach work on a community level. The most common activities included interest groups, school classes, or immigrant organisations (17). ANC also operate the national cervical cancer screening programme that is offered to all women who are

residents in Sweden between the ages of 23 and 64 (47). Cervical cancer screening tests are collected by ANC midwives, but the follow-up of abnormal test results are managed by gynecologists in hospital-based health care. The degree of participation in the organised cervical cancer screening programme between 1993 and 2005 was approximately 62% for women born in Sweden. The corresponding figure for immigrant women was significantly lower – 49% (48). During the last few decades, an increasing focus has been directed towards lifestyle habits such tobacco and alcohol use and physical activity and eating habits. The Swedish National Board of Health and Welfare emphasises the importance of promotion of health and prevention of disease. National guidelines for disease prevention methods in the Swedish health care system were published in 2011 by the NBHW (49). These guidelines address pregnant women as a special group of interest (49). Priorities and level of the intervention methods that are recommended in health care are based on an overall rating of the severity of the condition, efficacy of the method, and cost-effectiveness of the intervention. Health care interventions are principally divided into three levels based on structure, content, and the extent of an intervention: 1) brief advice (i.e., a short standardized advice without any follow-up; maximum 2-5 minutes); 2) counselling (i.e., a dialogue between the health care professional and the patient, aiming for individualised advice, usually 10 to 15 minutes, and various tools and a specific follow-up can be added; and 3) advanced counselling (i.e., a dialogue between the health care professional and the patient, usually longer than counselling characterized by individualized advice. Advanced counselling requires skills in the theory-based method used (49). A motivational interviewing technique in counselling is the current recommended method for ANC (23). Use of tobacco during pregnancy has adverse effects on fetal health (50-53). In Sweden, the proportion of pregnant women reporting smoking in early pregnancy has decreased from 31.4% in 1983 to 5.5% in 2014 (54). Recommended intervention for prevention of tobacco use during pregnancy is counselling (level 2). The self-assessment protocol "Alcohol Use Disorder Identification Test" (AUDIT) was introduced in ANC on a national basis in Sweden during the mid 2000s. The AUDIT protocol is used as a screening instrument during the first ANC visit to identify pregnant women who report harmful drinking habits before pregnancy (55). During 2013, 90.6% of all pregnant women completed the AUDIT-form and 5.6% of the pregnant women reported a harmful drinking habit before pregnancy (17). During pregnancy, the recommended intervention for harmful drinking habits is counselling (level 2). Obesity is a growing problem globally as well as in Sweden (56, 57). The risk of adverse pregnancy outcomes for the mother and child has been well studied (11, 58-61). Obese pregnant women consume more health care during pregnancy compared to pregnant normal weight women (17, 62). Advanced counselling (level 3) is recommended for pregnant women with unhealthy eating habits (49). The NBHW guidelines

recommend promotion of physical activity to the general population using counselling intervention (level 2). However, these guidelines do not present any recommendations for counselling on physical activity during pregnancy (49). It is known that regular physical activity during pregnancy has positive health effects, but the optimal type, intensity, frequency, and duration of physical activity needs further investigation (63). Midwives in ANC strive to adjust counselling and promote physical activities in relation to the individual needs of pregnant woman (64).

Prenatal diagnosis

Methods

Prenatal diagnosis includes methods used up to 22 weeks of gestation (65). Prenatal diagnosis methods refer to either a diagnostic instrument or a screening instrument used to assess the probability/risk of chromosomal aberrations or fetal abnormalities (65). In 2008, the Swedish Council on Health Technology Assessment published a report presenting the evidence on different prenatal diagnosis methods and the available evidence on different information approaches. Medical, ethical, social, and psychological as well as health-economy aspects were considered in the analysis (65). Obstetric ultrasound was introduced in the Swedish antenatal care system in the 1970s. Currently, nearly all pregnant women undergo a routine ultrasound examination at 17-20 weeks of gestation (66). Usually, trained midwives operate these ultrasound examinations (67). The aim of the examination is to determine expected date of delivery, singleton/multiple births, placental localisation, and to detect any fetal abnormality. Evaluation through a large randomized controlled multi-centre study was performed before the introduction of risk assessment of chromosomal abnormalities (i.e., the combined ultrasound and biochemical test, CUB) in Sweden in the early 2000s (68). The CUB test includes measuring fetal nuchal translucency, β-hCG, and PAPP-A in maternal blood. The CUB test assesses the risk for the most common chromosome abnormality, trisomy 21 (Down's syndrome) as well as for trisomies 13 and 18. The CUB test is performed at gestational age of 11 weeks to 13 weeks and 6 days. A Swedish study finds that CUB had sensitivity and test positive rates of 90% and 6%, respectively (69). To diagnose chromosomal abnormalities, invasive prenatal diagnostic methods are required such as amniocenteses (AC) or chorionic villus sampling (CVS). Both tests may include complete chromosomal analysis where a result can be expected within approximately two weeks. Currently, the most common mode of analysis is the QF-PCR examining trisomies 13, 18, and 21, where results can be provided within approximately one week. AC is recommended at 15 weeks of gestation or later due to the increased risk of miscarriage or club foot if performed before 15

weeks of gestation. CVS is carried out at earliest 11 weeks of gestation (70, 71, 72-74).

Information on prenatal diagnosis

The Swedish National Board of Health and Welfare has stipulated regulations on offered prenatal diagnosis by health care services, as well as the general information on prenatal diagnosis trusted to midwives at ANC, and detailed information provided by medical doctors, if indicated (75). The regulations emphasise the importance of information being provided in a manner that enable the expecting parents to make an informed decision. At ANC registration, the midwives first ask the expecting couple whether they want to receive general information on prenatal diagnosis. If the expecting parents accept the offer, the actual information should be provided at a later visit. In addition, expecting parents should be offered time to reflect between the time they receive information and the time they make a decision. The information should include the aim of prenatal diagnosis, a description of the methods used, and an evaluation of risk. Information should raise ethical aspects and be designed to meet the individual needs of the expecting parents (75). Hence, autonomy in decision-making is emphasised irrespective of the expecting parents' consent to prenatal diagnosis. The informed consent process requires that the patient evaluates and voluntarily decides which option to use (76). A review study on informed uptake of screening tests offered in health care concludes that it is unclear whether informed choice affects the uptake (77). Data published in 2009 show that 41% of the midwives reported that they have enough knowledge and skills to inform expecting parents on the second trimester ultrasound, and the corresponding figure for the CUB is 16%. Midwives request more education on ultrasound as well as the CUB (78). The same data reveal a high degree of concordance between the given information reported by midwives and the received information on prenatal diagnosis reported by pregnant women (78). A recent study investigating knowledge and information on prenatal diagnosis among midwives in one specific Swedish county reports that a majority of the midwives in the area stated that they have insufficient or no education on prenatal diagnosis methods or on Down's syndrome. Furthermore, almost all of the midwives in that area wanted more education on the subject (94%) (79). Different models on provision of information on prenatal diagnosis have been investigated (80-85). A Swedish study suggests if pregnant women are exposed to an information video in addition to oral and written information, the knowledge on prenatal diagnosis increases (83). Being exposed to an information video increases the degree to which pregnant women make an informed choice on the CUB compared to pregnant women who only have been given oral and written information (83). However, an information video neither increases the knowledge or degree of

informed choice regarding the second trimester ultrasound (84) nor does it affect pregnant women's anxiety or worries (85). Expecting parents seem to focus on prenatal diagnosis if offered an extended information visit in early pregnancy by a specially trained midwife. Those expecting parents who declined to receive extra information reported that it was due to that the extended visit was associated with participation in the CUB (80-82). The ethical complexity of prenatal diagnosis as well as the complexity of informing on prenatal diagnosis has been discussed in different academic disciplines and from different angels (76, 86-89). In a report on prenatal diagnosis, the Swedish National Council on Medical Ethics stresses that conflicting ethical values continuously need to be discussed and that the autonomy in decision-making is essential and is promoted by relevant information. Like all health care interventions, the prenatal diagnosis methods used should be thoroughly investigated with respect to prioritisations of provided health care and by that limits the options of methods being offered (90).

Work conditions

The theory of organisational empowerment is applied in research investigating work conditions within health care (91-93). The theory includes six conditions required for empowerment to take place: 1) opportunity for advancement, 2) access to information, 3) access to support, 4) access to resources, 5) formal power, and 6) informal power. Work environment is strongly associated with empowerment (94). A comparison between midwives in Australia, New Zealand, and Sweden shows that Swedish midwives report a high degree of autonomy/empowerment and managerial support, although a lower degree of professional recognition, skills, and resources compared to midwives in Australia and New Zealand (95). Midwives in Swedish antenatal care are satisfied with their work environment and value resources and staffing more than midwives working in hospitals. Scheduling the own work day is a feature of autonomy (96). Similar results are reported in a Norwegian study, where midwives in primary health care report a degree of supportive management and autonomous professional role higher than hospital-based midwives (97). Apparently, structural empowerment affects the degree of job satisfaction (98, 99).

Scientific methods

The scientific methods used in this thesis were determined by the research questions in the four studies. Both quantitative methods, including biostatistics and epidemiology, and qualitative methods were used.

Quantitative methods

Quantitative research is a systematic way to measure outcomes using observable numerical data that enables mathematical and statistical analysis. Quantitative data may be collected via instruments containing data on physical or psychological parameters or by transforming subjective information into an objective numerical scale (100). Epidemiology refers to the distribution and determinants of health-related states or events in a specified human population (101). The scientific approach to epidemiological research should be "systematic in performing observations and measurement", "rigorous in following the agreed systems", "reproducible for other scientists", and "repeatable" to ensure the phenomena under investigation are accurately represented (102).

Qualitative methods

The term "qualitative" originates from the Latin word qualia which means "the subjective qualities of conscious experience" (103). Qualitative research is defined as "an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem" (104). The qualitative research perspectives are based on the "ontological assumption" (i.e., realities are subjective, multiple, and socially constructed), the "epistemological assumption" (i.e., researchers and informants are interactive and inseparable), the "axiological assumption" (i.e., research is value-bound), and the "methodological assumption" (i.e., qualitative research is inductive, time and context-bound, and follows an emerging design). These four assumptions are essential for interpretation of qualitative research (104). A text (data) always involves multiple meanings and some degree of interpretation is always present when analysing a text (105).

Qualitative Content Analysis

In "Qualitative Content Analysis" (QCA) of a text, the first step is to read and re-read the text until a sense of the whole is achieved. Next, the text is condensed into meaning units/codes. These codes are merged into categories, the core feature of QCA. The last step in analysis is to identify the emerging theme of the material (105). According to Graneheim and Lundman, categories answer the question "what" and refer mainly to a descriptive level of the content (i.e., the manifest content), whereas themes answer the question "how" and refer to the latent content (i.e., the underlying meaning of the text) (105).

Validity in quantitative research

The website "Research Methods, Knowledge Base" describes validity as "the best available approximation to the truth of a given proposition, inference or conclusion" (106). Or expressed in another way, validity refers to "the degree to which a measurement measures what it intends to measure" (101) (i.e., a correlation between the theoretical definition and the operational definition) (1). Validity contains three general aspects: *i)* absence of systematic errors (i.e., bias); *ii)* coherence of measurement; and *iii)* coherence of theoretical and empirical definition of a phenomenon (1). Internal validity is investigated by analysis of coherence between the included items/subjects where one is considered as the "true" value. External validity addresses whether the results of a study can be generalised to other situations or persons (1). The reliability of data reflects whether the results would be repeated if research were replicated in the same context and with the same subjects. Objectivity addresses to what extent results of a study are affected by the researchers' personal interests (104).

Trustworthiness in qualitative research

Trustworthiness is the corresponding concept to validity used in quantitative research investigating the same questions as validity. Judging trustworthiness requires addressing four areas: 1) credibility – what is intended to be measured; 2) applicability – whether the findings are applicable to other subjects or contexts; 3) consistency – whether the findings are repeatable in the same context and subjects; and 4) confirmability – whether the findings affected by any personal interests or biases (104).

AIMS

The overall aims for this thesis were to investigate different aspects of the Swedish Maternal Health Care Register (MHCR) in regard to validity of register data, user experiences, opinions and use of the register, and register outcomes data. Additional aims were to investigate structural and organisational factors affecting the midwives' work situation in antenatal care and their experiences on informing expectant parents on prenatal diagnosis.

The specific aims and where these aims are addressed (i.e., the specific aims addressed in the specific papers) are listed below.

Paper I: To investigate the validity of data entered in the MHCR with respect to *i)* degree of coverage of specified variables, *ii)* internal validity of data, including sensitivity and specificity of binary variables, and *iii)* potential systematic errors in MHCR data.

Paper II: To investigate midwives' experiences, opinions, and use of the Swedish MHCR regarding their *i)* experiences using the MHCR web-application for data entry, *ii)* how the MHCR was used in their daily work, *iii)* how and to what extent MHCR data were utilized in operational planning of health services, and *iv)* users' opinions on potential improvement of the MHCR.

Paper III: To investigate background characteristics and pregnancy outcomes in relation to the use of prenatal screening methods and diagnostic procedures in Sweden by exploring *i)* guidelines on prenatal diagnosis in the counties of Sweden, *ii)* uptake of routine ultrasound examination, combined ultrasound and biochemical test (CUB), chorionic villus sampling (CVS) and amniocentesis (AC), and *iii)* background characteristics and pregnancy outcomes in relation to different prenatal screening and diagnostic procedures.

Paper IV: To investigate the current work situation for ANC midwives with respect to straining and supporting factors affecting the work situation and midwives' experiences on provision of information on prenatal diagnosis to expecting parents.

MATERIALS AND METHODS

Table 1. Overview of the study design of Paper I-IV

Paper	Study design	Data collection	Participants	Analysis
I	Quantitative study: Cross-sectional, retrospective study comparing data on pregnancy and delivery in the medical records and in MHCR	A first data collection was performed where data on pregnancy and delivery were extracted from medical records in Obstetrix® (Siemens). A data-set on the commensurable pregnancies registered in MHCR was retrieved. A second data collection was performed on a subset of the first data collection	The cohort included in total 878 pregnancies, in nine different counties, with data in both the medical records and in MHCR. A subset of the cohort included 150 pregnancies in three different counties.	Statistical analyses were performed for degree of coverage, agreement and correlation of data, and sensitivity and specificity for the binary variables. Analysis on the sub-set of the cohort was performed to evaluate the quality of the initial data extraction.
II	Quantitative study with a qualitative component: Cross-sectional questionnaire survey including free text responses	A questionnaire, sent by e-mail, including in total 62 items and free text spaces.	All eligible midwives working in antenatal care between January to March 2012 were invited to participate in the study. Final sample was N=989.	Parametric and non-parametric methods and logistic regression analyses were performed. Inductive content analysis on free text comments was used.
III	Quantitative study: Cross-sectional, retrospective study	Local guidelines on prenatal diagnosis were collected for the years 2011 to 2013 from all MHCA. Data on pregnancies registered in the MHCR 2011 to 2013 were extracted.	Local guidelines from the 43 Swedish MHCA for the years 2011, 2012 and 2013. Data on 284,789 pregnancies registered in MHCR during the same period; 2011 to 2013 was retrieved.	Biostatistical and epidemiological analyses, including calculation of odds ratios and their 95% confidence intervals in univariate and multivariable analyses.
IV	Qualitative study: Individual interviews	Semi-structured telephone interviews.	Purposive sampling of 15 midwives working in antenatal care in different MHCA in Sweden.	Qualitative content analysis.

Paper I

This was a cross-sectional retrospective study comparing data on pregnancy and delivery in the medical records and in the MHCR. Power estimation was performed before the study, and 900 medical records were judged to be of sufficient sample size to respond to the research questions under study. Data were collected from nine hospitals in Sweden, and 100 medical records at each hospital were included. These hospitals were chosen because they represented a variety of characteristics regarding geography, demography, and birth volumes. In addition, these hospitals were chosen because the co-authors were affiliated with five of the selected hospitals. The proximity of the authors to the hospitals was considered advantageous when supporting the local administrators in extracting data from the medical records. Inclusion criteria for the study were women with data in the medical records as well as in the MHCR. Consequently, exclusion criteria were lack of data in either of the data sources. The heads at

each of the nine hospitals gave their consent to extract data from the medical records for the study. An Excel protocol was developed to secure that data were extracted from the medical records in the same manner at all hospitals. Data were then registered manually by a contracted local administrator. At each clinic, 100 women with a delivery date from March 1st 2011 and with data in the MHCR were selected consecutively. The smaller clinics required a longer time to collect these data (March 1st to May 29th), whereas the data from large clinics were collected within a few days (March 1st to March 9th). Thereafter, data were transferred in encrypted form to the UCR, where the two datasets, the medical records and the MHCR, were combined. The final dataset included data on 878 delivered women. The retrieved variables from the medical records and the MHCR were as follows: date of first ANC visit, number of previous deliveries, maternal weight at first ANC visit, maternal height at first ANC visit, smoking at first ANC visit, use of snuff at first ANC visit, assessment of alcohol use before pregnancy with AUDIT, AUDIT-score, live-born child, estimated date of delivery (ultrasound), ultrasound examination at gestational age of 16-21 weeks, combined ultrasound and biochemical test, second trimester serum screening, chorionic villus sampling, amniocentesis, number of antenatal visits until estimated date of delivery, smoking at 32 weeks of gestation, use of snuff at 32 weeks of gestation, maternal weight at late pregnancy (last registered weight after week 35 of gestation), oral glucose tolerance test (OGTT), performed, 2-hour value of plasma glucose at OGTT, date of delivery, mode of delivery, elective or emergency caesarean section, singleton birth, multiple births, birth weight, and gender of new-born. In statistical analysis, data in the medical records were considered the gold standard. Proportions of data available in the medical records and in the MHCR as well as proportions of coherent data in both data sources were calculated for each variable. Degree of agreement was estimated using Cohen's kappa for categorical variables and Pearson's correlation coefficient was used for the normally distributed continuous data. Spearman's correlation coefficient was used to evaluate dates. Sensitivity and specificity were analysed for binary variables. Level of significance was set at 0.05 and SPSS version 19 was used for all calculations.

Paper II

This was a national cross-sectional questionnaire study. The data collection was performed from January 2012 to March 2012. All midwives who at the time of the study were working at an ANC were addressed as well as all senior consultant midwives (synonymous with antenatal care coordinators) with an exception of three senior consultant midwifes, since they were authors of this study (KP, IH, and YS). The questionnaire included 62 items divided into five sections: *i)* background characteristics of the participants, *ii)* design of the web-application, *iii)* data entry of individual data, *iv)* the user manual, and *v)* on-line

reports created by the users from the MHCR. The last section was sub-divided into two parts: the midwives exclusively involved in patient-related work and the midwives exclusively or in addition to patient-related work were engaged in administrative supervision. The items were formulated as open questions or with Likert-type scale options (0 = totally disagree and 5 = totally agree). In addition, space for free text comments was provided. The questionnaire was pilot-tested before the survey and minor changes were made. Prior to the study, information on the number of midwives employed at each MHCA was estimated to be 1863. The questionnaire was distributed by e-mail, via the senior consultant midwife in each MHCA to midwives working at ANC in the area. Invited participants completed the questionnaire and sent it to the senior consultant midwife, who sent all the questionnaires to the first author (KP). The questionnaires responded by the senior consultant midwives was sent to a secretary. These procedures were undertaken to protect anonymity. Data on background characteristics, and the preformed statements were registered in Excel and free text comments were recorded in a Word document. The Excel protocol data were transformed into SPSS for analysis. In the analysis, the participants were categorized into three groups: *i)* midwives engaged in patient-related work exclusively (group A); *ii)* midwives having both patient-related work tasks and administrative supervision tasks (group B); and *iii)* midwives exclusively engaged in supervision (group C). Analysis of the preformed statements was done using parametric and non-parametric methods. Odds ratios and their 95% confidence intervals were calculated using univariate and multivariable logistic regression analysis. The independent variables – i.e., background characteristics as well as the dependent variables recorded on the Likert-type scale on the preformed statements – were dichotomized. The free text comments were analysed using inductive content analysis. SPSS (versions 19 and 22) was used for all calculations.

Paper III

This was a retrospective cross-sectional epidemiological study. National data were retrieved from the MHCR between 2011 and 2013. Inclusion criteria were pregnancies registered in the MHCR with a date of delivery of a live or stillborn child of a gestational age of 22+0 to 43+0 weeks. In total 284,789 women and their new-borns were included in the study. In addition, all local guidelines used during the study period regarding prenatal diagnosis were collected from the senior consultant midwife (synonymous with antenatal care coordinator) in each MHCR. Variables extracted from the MHCR were number of previous deliveries, maternal weight at first ANC visit, maternal height, self-rated health before pregnancy, smoking before pregnancy, smoking at first ANC visit, smoking at 32 weeks of gestation, use of snuff before pregnancy, use of snuff at first ANC visit, use of snuff at 32 weeks of gestation, assessment of use of

alcohol before pregnancy with AUDIT, AUDIT score, educational level, country of origin, employment status, live or still born child, estimated date of delivery (ultrasound), ultrasound examination at gestational age of 16-21 weeks, combined ultrasound and biochemical test, second trimester serum screening, chorionic villus sampling, amniocentesis, counselling due to fear of childbirth, treatment of psychiatric disorder, (psychological or medical treatment), date of delivery, mode of delivery, if caesarean section, elective or emergency section, singleton birth, multiple birth, birth weight (singletons), and gender of infant. Some variables were used both as an independent and a dependent variable although in different analyses. All variables except for one were categorised into two groups or more. Birth weight was presented as a continuous variable. Categorical variables were analysed with frequencies and percentages and continuous variables were presented as their mean values and standard deviations (SD). In analysis of trends over the year, Linear-by-Linear Association was used. Test of difference between independent groups was analysed with One-Way ANOVA test and independent samples t-test for parametric data, corrected for homogeneity for variance if necessary. Pearson's Chi-Square test was used to test difference between groups of categorical variables. Level of significance was set at $p<0.05$. Odds ratios (OR) and their 95% confidence intervals (CI) were calculated in univariate and multivariable logistic regression analyses. SPSS (versions 22 and 23) was used for these calculations. A Venn diagram was created to present the uptake of CUB, CVS, and AC in the study sample and a figure presenting a map of Sweden was created to illustrate geographical differences in uptake of CUB. In this map, the 21 counties were categorized into four groups of CUB uptake rate: less than 10%; 10% to 29.99%; 30% to 69.99%; and 70% or more.

Paper IV

This study was a qualitative study using manifest and latent content analysis inspired by Graneheim and Lundman (105). Data were collected using semi-structured telephone interviews with each participant. All interviews were recorded digitally and transcribed into text. First, an interview guide was developed by the authors based on the literature, previous research, and their experiences of antenatal care. A pilot-interview was then undertaken, and was assessed positively, therefore included in the materials for analysis. After the third interview, a question about cooperation with physicians was added to the interview guide. Purposive sampling was used, aiming to recruit 12 to 15 midwives working in a variety of Swedish ANC settings regarding organization (private/public health care), volumes of surveyed pregnant women, demography, socio-economic status, and geographical regions. Participants varying in age and work year as a midwife were desired in the study. The antenatal care coordinator in each selected MHCA was informed about the

purpose of the study. A list of names and e-mail addresses of eligible midwives working in ANC were provided by the ACC. Thereafter, an e-mail with information on the study was sent to eligible midwives. In total, 24 midwives were contacted (including the pilot interview) by e-mail. Fifteen midwives accepted to participate in the study, three declined, and six did not reply to the invitation. The participants were provided oral and written information on the content of the study and were assured of their confidentiality. The voluntary nature of participation was emphasised as well as the option to terminate their participation at any time during the study. All participants signed an informed consent before the study. Saturation of data was assessed to be achieved after 14 interviews. To certify saturation of data, an additional interview was conducted; however, no further significant information was collected at that interview. Finally, fifteen participants from eleven MHCAs were included in the study. The participants were between 34 to 62 years of age (mean age 51.4 years) and reported work experience as midwives in antenatal care between 4 to 27 years with a mean of 12.6 years. All participants were females. The interviews were conducted from February 2015 to February 2016. The participants chose the date and time for the interviews, which lasted between 37 to 55 minutes with a mean time of 44 minutes. Before the interview, baseline information was collected on age, work experience as a midwife (years), work experience as a midwife in antenatal care (years), education other than nursing and midwifery, and whether the ANC was private or public.

Ethical approval and ethical considerations

Ethical approval was obtained from the Regional Ethics Committee in Umeå for Study III (Dno 2012-44-31M). Two complementary applications were submitted and approved (Dno 2012-407-31M, Dno 2014-407-31M). In the advisory statement (Dno 2012-44-31M), it was considered that no ethical approval was needed for Study I, II, and IV. Furthermore, no ethical objections were raised about the research projects.

Study I was a research project undertaken to investigate coverage and quality of data as well as exploring potential systematic errors with the aim to secure correctness and improve the quality of data in the MHCR. Individual data on patients were used for comparison of data in the medical records and corresponding data in the MHCR. The study did not evaluate individual patients; that is, the work task performed by health care professionals on registration of data in the MHCR was assessed. When pregnant women are registered at ANC, they are to be informed on the purpose of the MHCR and the possible use of register data in future research. Information includes the voluntariness of contributing with data to the quality register and the option to "opt-out". Information is usually provided via a poster at the ANC and to some extent by the midwives. Hence, by accepting to be a subject in the

MHCR, patients provide consent to participate in research using the register data.

The research questions included in Study II and Study IV investigated experiences and views by health care professionals on one specific work task (the MHCR) and on the work situation as a whole, thus no patients or patient data were involved. Study II was a questionnaire study where participants agreed to participate by responding to the questionnaire. In Study IV, data were collected by individual telephone interviews. Before the interviews, eligible participants were informed via e-mail about the purpose and design of the study. The ethics committee had comments on the information given on the study when recruiting participants. The information was then re-formulated where it was emphasised that their participation was voluntary. Signed consent by the participants was obtained before the study. Furthermore, before each interview, participants were informed that they could reject to answer any of the questions or at any time terminate their participation in the study. The research group concluded that participation in the study would not result in any risk of harm.

Study III was a cross-sectional, retrospective epidemiological study using register data to investigate background characteristics and pregnancy outcomes on pregnant women who had undergone prenatal diagnosis. The results from Study III were presented on aggregated level and no individual could be identified. No potential harm for the patients was identified by the research group. Therefore, individual consent to participate in the study was not regarded as necessary. The ethics committee reached the same conclusion

Statistical analysis

In Paper I, degree of agreement was estimated using Cohen's kappa for categorical data and Pearson's correlation coefficient was used for normally distributed continuous data. Spearman's correlation coefficient was used to evaluate dates. Sensitivity and specificity were analysed for binary variables. In Paper II, analysis of data was done using parametric and non-parametric methods. Odds ratios (OR) and their 95% confidence intervals were calculated using univariate and multivariable regression analysis. In Paper III, categorical variables were analysed with frequencies and percentages. Continuous variables were presented as their mean value and standard deviation (SD) and by median value and inter-quartile range (IQR). Continuous variables were tested for the assumption of normal distribution. Test of trend was analysed using Linear-by-Linear Association. Test of difference between independent groups were analysed with One-Way ANOVA test, and independent samples t-test for parametric data corrected for homogeneity for variance if necessary. The Pearson's Chi-Square test was used for test of difference between groups of

categorical data. Level of significance was set at $p<0.005$. SPSS (version 19, 22, and 23) was used in the analysis.

RESULTS

PAPER I: Internal validity of the Swedish Maternal Health Care Register

This cross-sectional observational study compared pregnancy and delivery data registered in the medical records with corresponding data registered in the MHCR. The medical record was considered the gold standard. In total, data on 878 pregnancies were collected from nine hospitals in Sweden. The hospitals represented a variety of volumes and demography as well as different levels of care – county, regional, and University hospitals. Analysis was performed regarding coverage in each of the data sources, degree of data available in both data sources, and degree of identical information in both data sources. Furthermore, analysis on sensitivity and specificity were performed. Degree of coverage of all investigated data in the MHCR varied from 90% to 100%. The variables on prenatal diagnosis methods presented the lowest coverage, amniocentesis (90.1%), chorionic villus sampling (90.0%), combined ultrasound and biochemical test (90.1%), second trimester screening (90.0%), and ultrasound examination at 16-21 gestational weeks (90.1%). In fact some variables demonstrated a degree of coverage in the MHCR higher than in the medical records: assessment of alcohol screening prior to pregnancy (yes/no; if "yes", the AUDIT score was provided), combined ultrasound and biochemical test (yes/no), estimated date of delivery by ultrasound, oral glucose tolerance test performed (yes/no); if "yes", 2-hour value of plasma glucose at OGTT, smoking at 32 gestational weeks (yes/no), use of snuff at 32 gestational weeks (yes/no), maternal weight, and last data entry after 35 gestational weeks. Eighteen out of the 27 variables demonstrated a proportion of data available in both data sources of 90% or more. An overall high agreement of data in the two data sources was found, varying from 73.9% to 99.7%. The lowest degree of agreement was for the variables "date of first ANC visit" and "number of ANC visits until estimated date of delivery". The highest degree of identical information in the two data sources was mainly identified on variables related to delivery such as singleton/multiple births, live born child, and gender of child (Table 2). In addition, sensitivity and specificity data were analysed on the binary variables with a response option of "yes" or "no". Data in the medical records were considered representing the true value. Most of the variables analysed demonstrated either a combination of high sensitivity and low specificity or the reverse, low sensitivity and high specificity (Table 2).

Table 2. Data in medical records and the Swedish Maternal Health Care Register (MHCR); comparison between the two data-sets using correlation analysis, and analysis of sensitivity and specificity for binary variables

Variable	Data source: Medical records		Data source: MHCR		Data available in both data sources		Identical information in both data sources		Correlation[a]	Sensitivity	Specificity
	n	%	n	%	n	%	n	%			
Variables collected at first antenatal care (ANC) visit											
Date of first visit in ANC (numerical)	877	99.9	868	98.9	867	98.7	685	79.0	0.878 (S)		
No of previous deliveries (numerical)	878	100	867	98.7	867	98.7	840	96.8	0.971 (P)		
Maternal weight at first ANC visit (numerical)	862	98.1	855	97.4	847	96.4	798	94.2	0.990 (P)		
Maternal height (numerical)	872	99.3	862	98.2	860	97.9	834	97.0	0.982 (P)		
Smoking at first ANC visit (Yes/No)	875	99.7	872	99.2	868	98.9	843	97.1	0.742 (C)	0.650	0.995
Use of Snuff at first ANC visit (Yes/No)	878	100	871	99.2	871	99.2	861	98.9	0.540 (C)	0.429	0.998
Assessment of alcohol screening prior to pregnancy (AUDIT)(Yes/No)	802	91.3	859	97.8	788	89.7	691	87.7	0.480 (C)	0.986	0.393
If Yes, AUDIT score (numerical)b	650/643	98.9	777/771	99.2	621	95.5	600	96.6	0.989 (P)		
Variables collected at 4 to 16 weeks postpartum											
Prenatal diagnostics											
Amniocentesis (AC) (Yes/No)	875	99.7	791	90.1	788	89.7	772	98.0	0.754 (C)	0.743	0.991
Chorion Villus Sampling (CVS) (Yes/No)	875	99.7	790	90.0	787	89.6	778	98.9	0.176 (C)	0.167	0.995
Combined Ultrasound and Biochemical screening (CUB) (Yes/No)	780	88.8	791	90.1	700	89.7	665	95.1	0.888 (C)	0.936	0.957
Second trimester Serum Screening (Yes/No)	849	96.7	790	90.0	767	87.4	671	87.4	0.002 (C)	0.043	0.958
Ultrasound examination at 16 – 21 gestational weeks (Yes/No)	862	98.2	791	90.1	779	88.6	755	96.9	0.064 (C)	0.979	0.800
Estimated date of delivery (ultrasound) (numerical)c	871	99.2	874	99.5	868	98.9	781	90.0	0.946 (S)		
Oral Glucose Tolerance Test (OGTT) performed (Yes/No)	869	98.9	877	99.9	868	98.9	842	97.0	0.854 (C)	0.880	0.982
If Yes, 2-hour value of plasma glucose at OGTT (numerical)d	100/48	48.0	104/97	93.3	46	46.0	34	73.9	0.902 (P)		
Smoking at 32 gestational weeks (Yes/No)	858	97.7	876	99.8	856	97.5	849	99.1	0.864 (C)	0.821	0.998
Use of Snuff at 32 gestational weeks (Yes/No)	832	94.8	876	99.8	830	94.5	826	99.5	0.712 (C)	0.625	0.999
Maternal weight, last data entry after 35 gestational weeks (numerical)	777	88.5	843	96.0	760	86.6	706	92.9	0.989 (P)		
No. of ANC visits until estimated date of delivery (numerical)	877	99.9	868	98.9	867	98.7	627	72.3	0.915 (P)		
Date of delivery (numerical)	878	100	878	100	878	100	842	95.9	0.989 (S)		
Live born child (Yes/No)	878	100	878	100	878	100	874	99,5	0.598 (C)	0.999	0.500
Birth weight (numerical)	876	99.8	869	99.0	868	98.9	813	93.7	0.989 (P)		
Gender of infant (Boy/Girl/Sex unknown)	878	100	874	99.5	874	99.5	862	99.2	0.973 (C)		
Singleton birth/multiple births	877	99.9	878	100	877	99.8	875	99.7	0.908 (C)		
Mode of delivery (vaginal/instrumental vaginal/caesarean section)	876	99.8	876	99.8	874	99.5	857	98.0	0.946 (C)		
If caesarean section, elective CS/emergency CS[e]	130/115	88.5	129/128	99.2	110	84.6	102	92.7	0.841 (C)		

[a] Correlation analysis: C = Cohen's kappa, P = Pearson´s correlation coefficient, S = Spearman`s correlation coefficient.

[b] Measures are calculated for those who have undergone alcohol screening (n = 650). The denominator is the total no of "Yes" responses. Denominator in the Medical records =650. Denominator in the MHCR = 771.

[c] Measures are calculated for those who have undergone ultrasound.

[d] Measures are calculated for those who have undergone OGTT. The denominator is the total no of "Yes" responses. The denominator for the medical records = 100. The denominator for the MHCR = 104.

[e] Measures are calculated for those who have undergone caesarean section. The denominator is the total no of "Yes" responses. The denominator for the medical records = 130. The denominator for the MHCR = 129.

The recollection of data improved the proportion of data available in both data sources, ranging from 69.2% (2-hour value of plasma glucose at OGTT) to 100%. In the re-collection of data, a proportion of 100% of data available in both data sources was found for 17 out of the 27 variables. Furthermore, the proportion of data with identical information in the two data sources increased. The lowest proportion was shown for the variable number of antenatal visits (64.0%). Possible systematic errors were identified for two variables, second trimester screening and number of ANC visits. The variable second trimester screening demonstrated identical information in both data sources for 87.4%. One of the included hospitals reported an unexpected large number of performed second trimester screenings, and the reported number was not consistent with the clinical practise. This issue was discussed with midwives working in the catchment area of the hospital, suggesting that the variable probably had been misunderstood and incorrectly reported in the register. The variable, number of ANC visits, showed an agreement in both data sources for 72.3% of the cases. A misfit of +1 visit was seen in 19.3% of the cases. The variation of incorrect values ranged from -7 visits to +8 visits. The information addressing this variable in the web-application was defined as number of ANC visits to meet a midwife (noted in the medical record) until estimated date of delivery as established by ultrasound.

PAPER II: User perspectives on the Swedish Maternal Health Care Register

This cross-sectional questionnaire survey addressed all midwives working at Swedish antenatal care units and was conducted between January 2012 and March 2012. During the study period, the estimated number of eligible midwives was 1,863 and the total response rate was 53.1% (N=989). The response rate varied between different counties from 21.5% to 77.6%. The largest county, Stockholm county, accounted for approximately 25% of all births in Sweden and had a response rate of 46.2% (191/413). The participants working as senior consultant midwives (synonymous with antenatal care coordinators) had a response rate of 92.5% (37/40). The mean age of all participants was 51.1 years, ranging from 27 to 69 years. The mean age of participants engaged in administrative supervision exclusively or as a part of work in addition to the patient-related work (group B and C) were significantly higher (53.6 years) in relation to participants who worked exclusively with patient-related work (group A) (50.8 years $p=0.002$). Including all participants, the mean number of work years as a midwife was reported to be 21.4 years, and the mean number of work years as an ANC midwife was 13.3 years. A majority of the participants (80.4%) reported entering data in the register at least once a week.

The main findings on the preformed statements in the questionnaire were that most of the participants valued the web-application for registration of data. However, entering data in the register was perceived as burdensome by a majority (70.7%) of the participants in group A. Of the participants included in group A, 9.5% responded that they regularly accessed data on pregnant women visiting their ANC clinic. The corresponding figure for participants included in group B and C were 55.6%. The benefit of the register was questioned by 44.7% of the participants in group A, whereas the corresponding figure for participants included in group B and C was 18.5%. Of the participants included in group B and C, 66.7% saw their colleagues as interested in the clinic register data, and 54.7% used register data to compare their own ANC clinic with other levels of health care (regions, counties, and country) (Table 3).

Table 3. Response rate and level of agreement on formulated statements related to the Maternal Health Care Register

	Response rate[a]	Values[b]						
		Totally disagree					Totally agree	Summary of value
	n (%)	0	1	2	3	4	5	3 to 5
1. Statements responded by all participating midwives (N=989)								
It is easy to get an overview	947 (95.8)	9 (0.9)	21 (2.2)	64 (6.8)	261 (27.6)	359 (37.9)	233 (24.6)	853 (90.1)
It is easy to orient myself	948 (95.9)	8 (0.8)	17 (1.8)	60 (6.3)	248 (26.2)	390 (41.1)	225 (23.7)	863 (91.0)
The start page has an appealing layout	866 (87.6)	33 (3.8)	52 (6.0)	134 (15.5)	345 (39.8)	196 (22.6)	106 (12.2)	646 (74.7)
The colours are appealing	844 (85.0)	9 (1.1)	35 (4.1)	99 (11.7)	295 (35.0)	273 (32.3)	133 (15.8)	700 (83.0)
The font is easy to read	943 (95.0)	3 (0.3)	8 (0.8)	33 (3.5)	188 (19.9)	397 (42.1)	314 (33.3)	898 (93.5)
The text is easy to understand	948 (95.9)	3 (0.3)	8 (0.8)	30 (3.2)	184 (19.4)	428 (45.1)	295 (31.1)	907 (95.7)
The font size works well	947 (95.8)	2 (0.2)	2 (0.2)	24 (2.5)	144 (15.2)	402 (42.4)	373 (39.4)	919 (97.0)
I get the information I need about the register	861 (87.1)	19 (2.2)	22 (2.5)	68 (7.9)	236 (27.4)	328 (38.1)	188 (21.8)	752 (87.3)
The Web-application functions well for registration	943 (95.3)	10 (1.1)	14 (1.5)	44 (4.7)	187 (19.8)	420 (44.5)	268 (28.4)	875 (92.8)
Register manual								
I have read the manual (proportion of "yes" answer)	493 (51.5)							
The text is easy to understand	462 (93.7)	2 (0.4)	2 (0.4)	14 (3.0)	126 (27.3)	236 (51.2)	82 (17.7)	444 (96.1)
The manual gave me the information I needed	459 (93.1)	3 (0.7)	2 (0.4)	17 (3.7)	121 (26.4)	219 (47.7)	97 (21.1)	437 (92.5)
Registration of data at first data entry								
The questions are easy to understand	966 (97.7)	3 (0.3)	2 (0.2)	12 (1.2)	83 (8.6)	379 (39.2)	487 (50.4)	949 (98.2)
The questions come in a logical order	918 (92.8)	4 (0.4)	4 (0.4)	19 (2.1)	117 (12.7)	388 (42.3)	386 (42.0)	891 (97.1)
Registration of data at second data entry								
The questions are easy to understand	953 (96.4)	1 (0.1)	2 (0.2)	16 (1.7)	128 (13.4)	425 (44.6)	381 (40.0)	934 (98.0)
The questions come in a logical order	916 (92.6)	2 (0.2)	7 (0.8)	22 (2.4)	132 (14.4)	412 (45.0)	341 (37.2)	885 (96.6)
2.Statements responded by midwives in group A[c] (n=880)[d]								
I regularly access data on pregnant women who visit my clinic	842 (95.7)	481 (57.1)	182 (21.6)	99 (11.8)	55 (6.5)	11 (1.3)	14 (1.7)	80 (9.5)
The register is helpful in my clinical work	750 (85.2)	289 (38.5)	163 (21.7)	118 (15.7)	127 (16.9)	32 (3.6)	21 (2.8)	180 (24.0)
The register is burdensome	843 (95.8)	64 (7.6)	78 (9.3)	105 (12.5)	215 (25.4)	186 (21.9)	197 (23.4)	596 (70.7)
I gain a more coherent picture of the pregnant woman by registering data in the register	809 (91.9)	285 (35.2)	198 (24.5)	131 (16.2)	147 (18.2)	36 (4.4)	12 (1.5)	195 (24.1)
I question the benefit of the register	789 (89.7)	201 (25.5)	148 (18.8)	87 (11.0)	158 (20.0)	83 (10.5)	112 (14.2)	353 (44.7)
3. Statements responded by midwives in group B[e] (n=84) and C[f] (n=24). In total n=108[d]								
I regularly access data on pregnant women who visit my clinic	99 (91.7)	20 (20.2)	11 (11.1)	13 (13.1)	22 (22.2)	17 (17.2)	16 (16.2)	55 (55.6)
The register is helpful in my clinical work	85 (78.7)	15 (17.6)	6 (7.1)	11 (12.9)	24 (28.2)	15 (17.6)	14 (16.5)	53 (62.4)
The register is burdensome	98 (90.7)	19 (19.4)	24 (24.5)	18 (18.4)	19 (19.4)	12 (12.2)	6 (6.1)	37 (37.8)
The register is helpful in my administrative work	94 (87.0)	17 (18.1)	7 (7.4)	8 (8.5)	15 (16.0)	28 (29.8)	19 (20.2)	62 (66.0)
I gain a more coherent picture of the pregnant woman by registering data in the register	80 (74.1)	21 (26.3)	8 (10.0)	13 (16.3)	18 (22.5)	14 (17.5)	6 (7.5)	38 (47.5)
I use register data in our operational planning	91 (84.3)	27 (29.7)	11 (12.1)	7 (7.7)	13 (14.3)	22 (24.2)	11 (12.1)	46 (50.5)
I base financial decisions on data from the register	79 (73.1)	37 (46.8)	8 (10.1)	10 (12.7)	14 (17.7)	8 (10.1)	2 (2.5)	24 (30.4)
I use register data to describe the burden of care for my clinic	95 (88.0)	24 (25.3)	7 (7.4)	12 (12.6)	13 (13.7)	23 (24.2)	16 (16.8)	52 (54.7)
I use register data to compare my clinic with other levels of health care (regions, counties, Sweden)	96 (88.9)	22 (22.9)	12 (12.5)	12 (12.5)	8 (8.3)	24 (25.0)	18 (18.8)	50 (52.1)
I present register data to my colleagues at the clinic	96 (88.9)	25 (26.0)	10 (10.4)	7 (7.3)	14 (14.6)	20 (20.8)	20 (20.8)	54 (56.3)
I perceive my colleagues as interested in clinic data	90 (83.3)	15 (16.7)	3 (3.3)	12 (13.3)	21 (23.3)	24 (26.7)	15 (16.7)	60 (66.7)
I provide register data to my supervisors	95 (88.0)	32 (33.7)	11 (11.6)	8 (8.4)	9 (9.3)	19 (20.0)	16 (16.8)	44 (46.3)
I provide register data for development of health care	84 (77.8)	57 (67.9)	13 (15.5)	7 (8.3)	5 (6.0)	1 (1.2)	1 (1.2)	7 (8.3)
I question the benefit of the register	92 (85.2)	52 (56.5)	19 (20.7)	4 (4.3)	4 (4.3)	3 (3.3)	10 (10.9)	17 (18.5)

[a] Response rate is the number of responding participants divided by 989

[b] Values on a scale from 0 to 5 where 0=totally disagree and 5=totally agree

[c] Group A included midwives exclusively engaged in patient-related work tasks

[d] One participant did not fill in type of work executed

[e] Group B included midwives engaged in both patient-related work tasks and administrative supervision

[f] Group C included midwives exclusively engaged in administrative supervision

Odds Ratios and their 95% confidence intervals were calculated using univariate and multivariable logistic regression analysis on the following statements: The register is helpful in my clinical work; I regularly access data on women who visits my clinic; The register is burdensome; and I question the benefit of the register. There was a statistically significant difference between participants included in group A in relation to participants included in group B and C for the statement I regularly access data on women who visit my clinic ($p<0.001$; COR=11.79 CI 95% 7.43-18.69). When adjusting for age and work years, the adjusted odds ratio remained highly increased (AOR=11.07; ACI 95% 6.83-17.91). Furthermore, there was also a statistically significant difference between participants working at a public ANC in relation to participants working at a private ANC for the statement I question the benefit of the register (COR=1.70; CI 95% 1.15-2.48). After adjusting for work characteristics (i.e., participants included in group A or in group B and C), the adjusted odds ratio further increased (AOR=1.79; ACI 95% 1.21-2.65). The free text comments revealed five categories and 15 sub-categories (Table 4).

Table 4. Overview of categories and sub-categories for free text answers

Categories	Sub-categories
Duplicating registration	Time consuming registration Data available in other sources Work task for someone else
Navigating the Web-application	Old fashioned layout Difficulties operating the system Patients' identity exposed
Understanding the variables	Interpretation of variables Redundant variables Lack of relevant variables
Needing education on the system	Lack of introduction to the system Insufficient user instructions Need of continuous information
Use of data in daily work	Questioning the usefulness Mapping the situation Under-utilized source

To enter data in the register was perceived as a time consuming work task and it was noted by the participants that a direct electronic transferral of data from the medical records to the register would simplify the assignment. Furthermore, to enter data was perceived as something not necessarily a midwife had to do a secretary or other administrational staff could just as well perform this work task. Some of the participants found that some variables included in MHCR, such as prenatal diagnosis, were redundant. However, the participants also suggested some new variables for inclusion in the register – e.g., infertility, in vitro fertilization, inter current-diseases during pregnancy, medical complications during pregnancy and birth, and physical activity during pregnancy.

PAPER III: Prenatal diagnosis in Sweden 2011 to 2013 – a register-based study

This retrospective cross-sectional epidemiological study analysed data on pregnancies retrieved from the Swedish Maternal Health Care Register and the Swedish Pregnancy Register from 2011 through 2013. Almost all Swedish counties (20 of 21) had issued written guidelines on offers on prenatal diagnosis during the first and second trimester. The guidelines remained unchanged in all counties but two during the study period. CUB was offered to all pregnant women in six counties and to older pregnant women in nine counties. CUB was not offered at all in five counties. In one county, CUB was offered on indication of anxiety related to pregnancy. The invasive prenatal diagnosis procedures AC or CVS were offered in all counties. During 2013, the uptake of CUB varied between the counties from 2.2% to 80.3%. Figure 1 shows the 21 counties and uptake of CUB during 2013.

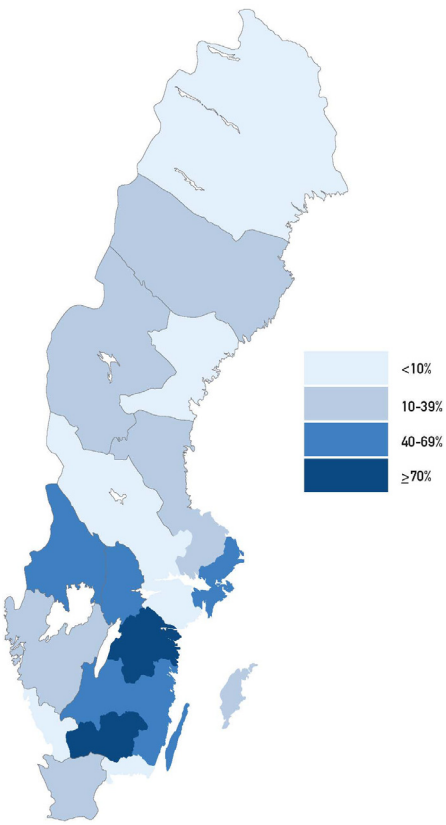

Figure 1. Map of Sweden indicating the 21 counties and Combined Ultrasound and Biochemical test (CUB) uptake, 2013.

The data set included 284,789 pregnant women with a date of delivery from January 1st 2011 to December 31st 2013. Almost all women were examined with a routine ultrasound during pregnancy (97.6%). The proportions of women examined with CUB, CVS, or AC were 33.0%, 1.1%, and 2.6%, respectively. The uptake of CUB increased significantly during the study, period, from 29.8% (2011) to 36.2 (2013) ($p<0.001$). The proportions of women examined with CUB, CVS, AC, or any combination of these procedures are presented in Figure 2.

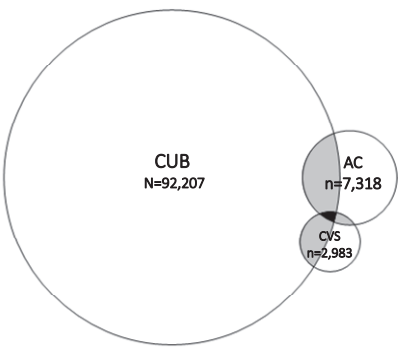

Figure 2. Pregnant women that were examined with CUB, AC and CVS

During 2013, the uptake of CUB varied between counties from 2.2% to 80.3%, and the county accounting for 26.1% of all the births in Sweden (Stockholm County) demonstrated an uptake of 53.2%. Table 5 presents the background characteristics and outcomes on pregnant women who had been examined with CUB, CVS, or AC and those who had not undergone any of these prenatal diagnosis procedures (defined as "all others"). Mean age for pregnant women who underwent CUB, CVS, or AC was 31.4, 33.79, and 33.65 years, respectively. The corresponding figure for women included in the group "all others" was 28.84 years. Those women who had undergone CUB, CVS, or AC reported Sweden as country of birth in 84.5%, 85.4, and 81.8% of the cases, respectively. The corresponding proportion for women included in the group "all others" was significantly lower, 76.7% ($p<0.001$). A relatively high percentage of women who had undergone CUB, CVS, or AC reported having a university level education (64.8%, 73.6%, and 61.6%, respectively), whereas a significantly lower percentage of women (44.0%) in the group "all others" reported having a university level education ($p<0.001$) (Table 5).

Table 5. Background characteristics and pregnancy outcomes in relation to prenatal screening or diagnostic procedures in the Swedish Pregnancy Register 2011 to 2013 (N=284,789)

Variable	CUB[a] n=92,207		CVS[b] n=2983		AC[c] n=7318		All others[d] n=186,092		Test of difference[e]
	n	%	n	%	n	%	n	%	
Maternal age[f], primiparous women (years)									
Mean (SD)[g]	31.34 (5.17)		33.79 (5.74)		33.65 (6.11)		27.09 (4.58)		<0.001
Min-max	15.09-56.30		17.29-49.03		16.74-49.83		13-54		
Median (IQR)[h]	31.34 (7.32)		34.41 (8.38)		34.92 (9.15)		27.51 (6.41)		
Maternal age[f], multiparous women (years)									
Mean (SD)[g]	34.45 (4.45)		36.87 (4.65)		37.13 (4.66)		30.29 (4.52)		<0.001
Min-max	16.41-55.34		19.10-51.76		16.41-48.68		15-57		
Median (IQR)[h]	34.97 (5.72)		37.58 (5.66)		37.82 (5.45)		30.87 (6.07)		
Maternal age[f] in age-groups (years)									
<20	388	0.4	8	0.3	23	0.3	3,566	1.9	
20-24	5,863	6.4	99	3.3	313	4.3	32,702	17.6	
25-29	17,617	19.1	300	10.1	733	10.0	65,926	35.4	
30-34	31,792	34.5	649	21.8	1,314	18.0	62,944	33.8	
35-39	30,179	32.7	1,262	42.3	3,148	43.0	17,676	9.5	
40-44	6,093	6.6	628	21.1	1,675	22.9	2,991	1.6	
>44	270	0.3	36	1.2	109	1.5	211	0.1	
Body mass index (kg/m^2)									
Mean (SD)[g]	24.40 (4.34)		24.10 (4.10)		24.94 (4.52)		24.99 (4.80)		<0.001
Min-max	13.82-56.65		15.24-51.31		15.24-50.69		13.03-71.63		
Median (IQR)[h]	23.45 (5.0)		23.18 (5.0)		24.01 (5.0)		23.95 (6.0)		
<18.5	1,965	2.2	52	1.8	121	1.7	4,766	2.6	
18.5-24.99	56,723	63.2	1,918	66.3	4,140	58.2	103,359	57.2	
25-29.99	21,639	24.1	663	22.9	1,926	27.1	47,160	26.1	
30-34.99	6,863	7.6	195	6.7	652	9.2	17,741	9.8	
35.39.99	1,992	2.2	48	1.7	203	2.9	5,744	3.2	
≥40	629	0.7	18	0.6	68	1.0	2,071	1.1	
Educational level									
Elementary school	3,242	4.1	69	2.7	334	5.3	17,353	11.2	<0.001
High school	24,324	31.1	608	23.7	2,078	33.1	69,523	44.8	
University	50,763	64.8	1,887	73.6	3,869	61.6	68,302	44.0	
Main occupation									
Employed	72,519	80.3	2,439	83.7	5,582	77.8	118,371	65.0	<0.001
Student	6,467	7.2	146	5.0	524	7.3	24,121	13.3	
Parental leave	5,059	5.6	149	5.1	459	6.4	15,002	8.2	
Unemployed	3,320	3.7	78	2.7	294	4.1	11,601	6.4	
Sick leave	1,306	1.4	36	1.2	119	1.7	3,009	1.7	
Other	1,610	1.8	66	2.3	194	2.7	9,897	5.4	
Country of birth									
Sweden	76,276	84.5	2,482	85.4	5,876	81.8	139,881	76.7	<0.001
Other Nordic countries[i]	904	1.0	31	1.1	74	1.0	1,406	0.8	
Europe[i]	3,971	4.4	102	3.5	332	4.6	8,617	4.7	
Africa	1,243	1.4	37	1.3	127	1.8	9,438	5.2	
Asia	6,132	6.8	196	6.7	590	8.2	18,955	10.4	
Other	1,727	1.9	57	2.0	180	2.5	4,007	2.2	
Smoking 3 months prior to pregnancy	9,583	10.5	229	7.7	751	10.3	28,659	15.6	<0.001
Smoking at first ANC[k] visit	3,445	3.8	76	2.6	347	4.8	12,144	6.6	<0.001
Smoking at 32 weeks of gestation	2,527	2.8	48	1.6	289	4.0	9,238	5.0	<0.001
Use of snuff 3 month prior to pregnancy	2,493	2.7	64	2.2	213	2.9	7,268	3.9	<0.001
Use of snuff at first ANC visit	646	0.7	22	0.7	85	1.2	2,134	1.2	<0.001
Use of snuff at 32 weeks of gestation	385	0.4	13	0.4	41	0.6	1,303	0.7	<0.001
Alcohol screening (AUDIT)[l]	81,686	90.3	2,568	88.4	6,313	86.3	158,335	87.0	<0.001
AUDIT-score[m]									
Mean (SD)	2.34 (1.96)		2.26 (1.74)		2.12 (1.90)		2.11 (2.32)		
Min-max	0-38		0-18		0-29		0-40		
Median (IQR)[h]	2.00 (2)		2.00 (2)		2.00 (2)		2.00 (3)		
≤5p	76,786	94.5	2,462	96.3	6,012	95.7	82,067	94.6	<0.001
≥6p	4,485	5.5	95	3.7	270	4.3	4,703	5.4	
Self-rated health prior to pregnancy									
Very good	25,990	33.0	834	32.5	1,887	30.5	44,643	28.3	<0.001
Good	44,563	56.6	1,433	55.9	3,489	56.5	93,611	59.4	
Neither good nor poor	5,877	7.5	217	8.5	583	9.4	14,047	8.9	

Poor	1,817	2.3	64	2.5	187	3.0	4,334	2.7	
Very poor	440	0.6	15	0.6	34	0.6	1,056	0.7	
Counselling due to fear of childbirth	8,900	9.7	324	10.9	745	10.2	12,023	6.5	<0.001
Treatment of psychiatric disorder	6,002	6.5	185	6.3	533	7.3	11,275	6.1	<0.001
Gestational age (days)									
Mean (SD)[g]	278.0 (13.7)		276.6 (15.0)		276.5 (15.4)		278.0 (13.8)		0.326
Min-max	154-301		158-300		157-301		154-301		
Median (IQR)[h]	280.0 (13.0)		279.0 (13.0)		279 (15.0)		280 (13.00)		
Mode of delivery									
Vaginal	6,885	73.9	2,079	70.2	5,133	70.3	145,486	78.5	<0.001
Instrumental	6,376	6.9	163	5.5	392	5.4	12,468	6.7	
Caesarean section	17,574	19.1	721	24.3	1,772	24.3	27,405	14.8	
Caesarean section (CS) [n]									
Elective CS[n]	8,650	49.3	297	58.7	916	51.7	10,700	39.1	<0.001
Emergency CS[n]	8,893	50.7	422	41.3	855	48.3	16,639	60.9	
Birth weight (grams)[o]									
Mean (SD)[g]	3549 (552)		3531 (585)		3510 (620)		3539 (557)		0.001
Min-max	310-6270		400-5710		370-5776		300-6640		
Median (IQR)[h]	3560 (665)		3555 (686)		3548 (706)		3545 (680)		

[a] CUB = Combined Ultrasound and Biochemical test
[b] CVS = Chorionic Villus Sampling
[c] AC = Amniocentesis
[d] All others = Pregnant women who did not undergo any of the prenatal diagnostic procedures CUB, CVS or AC
[e] Test of difference between the two groups; pregnant women who underwent CUB and "all others" using t-test for continuous variables and Pearson's Chi-Square test for categorical variables
[f] Maternal age at delivery
[g] SD = Standard Deviation
[h] IQR = Interquartile Range
[i] Other Nordic countries includes Norway, Finland, Iceland and Denmark
[j] The Nordic countries excluded
[k] Antenatal care
[l] Assessment of use of alcohol prior to pregnancy with screening instrument Alcohol Use Disorder Identification Test (AUDIT)
[m] AUDIT score range from 0 to 40
[n] Caesarean section
[o] Singletons exclusively included in analysis

The odds ratio for undergoing CUB at maternal age of 35 years or older was highly increased (4.36; 95% CI 4.28-4.45). Table 6 presents univariate and multivariable logistic regression analysis for the uptake of CUB in relation to specific background characteristics. Education level demonstrated a strong impact on the likelihood of being examined using the CUB. Having received counselling due to fear of childbirth or reported psychiatric treatment significantly increased the OR for CUB. Women born outside of Sweden had a decreased OR for CUB (Table 6).

Table 6. Univariate and multivariable logistic regression analysis for undergoing Combined Ultrasound and Biochemical test (CUB) in relation to maternal age divided into two age groups and to specified background characteristics

Variable	Maternal age <35 years				Maternal age ≥35 years			
	Crude OR	CI 95%	Adjusted OR*	Adjusted CI 95%	Crude OR	CI 95%	Adjusted OR*	Adjusted CI 95%
Educational level								
Elementary school, high school	1		1		1		1	
University level	2.03	1.98-2.07	1.79	1.75-1.83	1.86	1.79-1.93	1.53	1.47-1.61
Body mass index (kg/m^2)								
<25	1		1		1		1	
≥25	0.75	0.73-0.76	0.84	0.82-0.86	0.65	0.63-0.68	0.76	0.73-0.80
Main occupation								
Employed, student, parental leave	1		1		1		1	
Unemployed, sick leave, other	0.51	0.49-0.53	0.70	0.67-0.74	0.46	0.44-0.49	0.64	0.59-0.70
Country of birth								
Sweden	1		1		1		1	
Other	0.60	0.58-0.61	0.76	0.74-0.79	0.55	0.53-0.57	0.74	0.70-0.78
Smoking at first visit at antenatal care								
No	1		1		1		1	
Yes	0.62	0.59-0.65	0.87	0.82-0.92	0.59	0.54-0.64	0.74	0.66-0.84
Self-rated health prior to pregnancy								
Very good and good	1		1		1		1	
Poor and very poor	0.85	0.74-0.98	0.96	0.82-1.13	0.62	0.50-0.76	0.80	0.63-1.02
Counseling due to fear of childbirth								
No	1		1		1		1	
Yes	1.41	1.36-1.46	1.38	1.32-1.45	1.40	1.32-1.48	1.27	1.18-1.28
Treatment of psychiatric disorder								
No	1		1		1		1	
Yes	1.03	0.99-1.08	1.15	1.09-1.22	1.04	0.98-1.11	1.16	1.05-1.28

*Adjusted for all other variables included in the analysis

PAPER IV: "The computer deprives me of my time with patients" – Swedish midwives' experiences in antenatal care

This qualitative study collected data using semi-structured telephone interviews with each participant. Analysis was performed using manifest and latent content analysis. In total, 15 participants were included in the study. The overall emerging theme "Responsibility is rewarding and demanding" describes the participants' satisfaction with their work situation, although it was considered demanding in several aspects. Well-defined structures regulating work and valuable collaboration in the chain of health care for pregnant women were supportive factors. The administrative work load and some of the organisational factors out of the midwives' control were reported as aggravating work performance. Informing expecting parents on prenatal diagnosis was perceived as challenging. Themes, categories, and their sub-categories are presented in Table 7.

Table 7. Theme, categories and their sub-categories

Theme	Category	Sub-category
Bearing responsibility is rewarding and demanding	Depending on administrative tools and supportive professionals	Administrative work is a necessity although strenuous Assistants can facilitate the work Head's understanding facilitates the mission
	Developing as a health professional	Developing self-knowledge and competence Alone and together at the same time The weight of continuing education Autonomy is essential for work satisfaction Rewarding moments in daily work
	Coping with responsibility and demanding work tasks	Economic responsibility disseminated to the individual midwife Being disrupted during encounters is stressful Being available for the patient Immigrant status increases the demands in antenatal care Coping with changing work load exposure
	Operating in the chain of care	Functions underpinning the work Referring to higher level of health care
	Counselling on prenatal diagnosis – a mission like no other	Counselling on prenatal diagnosis is challenging Emerging ethical dilemmas for all involved Is this really my work task?

The category "Depending on administrative tools and supportive professionals" addresses structures affecting how midwives may conduct their work tasks. Most participants perceived administrative work as strenuous. It was discussed that an assistant present at the ANC could help with various work tasks not requiring the skills of a midwife such as administrative work tasks like ordering supplies. A head who understood the content and nature of antenatal care was appreciated as significantly supportive for daily work in contrast to a head with limited understanding of the ANC mission.

The category "Developing as a health professional" describes different opportunities for midwives to develop in their professional role. Scheduled time for counselling related to their encounters with patients was valued as it was seen as an opportunity to reflect on emotional reactions to patients as well as on medical issues. Working as a midwife in ANC was perceived a solitary mission. A permissive atmosphere allowing midwives to ask for advice and having confidence in colleagues' competence was reported important. Continuing education was important to keep informed on new knowledge and to improve the provision of the own health care services. Participants with extensive ANC experience expressed a sense of being in control of the work tasks and the work situation and being able to individually plan work hours. The work was considered as a source of joy in itself. Encounters with women of different ages and during repeated pregnancies were appreciated as rewarding, professionally as well as personally.

The category "Coping with responsibility and demanding work tasks" addresses stressful factors influencing the work situation. In counties with performance-based funding of health care, economic aspects were permanently on the

agenda and some midwives perceived this as burdensome. Another stressful feature at ANC was the unscheduled visits by pregnant women, as these visits interrupted the planned visits as every unscheduled visit had to be regarded as an emergency. The demand for availability regarding opening hours, telephone hours, and e-mail contact was considered an obvious benefit for the patient although creating a stressful work situation for the midwife. Although usually perceived manageable, the overall work load was reported as high. If needed, pregnant women were always prioritised before other patient categories. Working alone or only with one colleague could be seen as stressful, especially in relation to absences or time off from work, as no other midwife could take over the work tasks. The increased number of asylum seeking women in Sweden was also seen as a challenge as the shortage of skilled interpreters resulted in communication and cultural difficulties.

The category "Operating in the chain of care" describes structures that support the chain of health care professionals surveying pregnant women – i.e., midwives and general practitioners in primary health care as well as obstetricians in hospital-based health care. The internet-based local ANC clinical guidelines were highly valuable for daily work. The team of a ACO and ACC, providing continuing education and local guidelines, were seen as essential in safe-guarding the assignments and quality improvement in ANC. The possibility to refer pregnant women to the hospital (i.e., a higher level of health care) was considered important. Overall, collaboration with hospitals was very valuable.

The last category, "Counselling on prenatal diagnosis – a mission like no other", reflects different aspects of the challenges midwives experience when informing expecting parents on prenatal diagnosis without allowing personal opinions to affect the information the patients use to make informed decisions. In general, midwives considered their knowledge on prenatal diagnosis as sufficient, although informing on the subject was perceived challenging. To inform patients about the CUB and the associated risk assessment were specifically difficult. Particular challenges occurred when informing either highly educated expecting parents or expecting parents with no or very limited pre-understanding of prenatal diagnosis. Highly educated expecting parents sometimes asked questions that could uncover a midwife's insufficient knowledge. Informing expecting parents with no or limited pre-understanding of prenatal diagnosis was recognized as a task requiring special skills. The perceived increased focus on prenatal diagnosis by the health care system as well as by expecting parents was questioned. Some participants raised concerns about the fundamental value of human dignity and rights with respect to methods aimed to detect Down's syndrome. Furthermore, some participants raised concerns about the inequality regarding offers on prenatal diagnosis in different counties as well as the unequal request of prenatal diagnosis by highly

educated expecting parents compared to those with a lower educational level. Divergent opinions were expressed about who was best suited to inform expecting parents about prenatal diagnosis – ANC midwives or specialists in the subject.

Table 8. Overview of results Paper I–IV

	Paper I	Paper II	Paper III	Paper IV
The Maternal Health Care Register: manually registered data	Most variables demonstrated a high degree of coverage in MHCR, 90.0% to 100%. Identical data in both MHCR and the medical records ranged from 73.9% to 99.7%. Possible systematic errors were found for two variables, i.e. "second trimester serum screening" and "number of ANC-visits".	The web-application used for the MHCR was valued positively, and most included variables were considered relevant and useful. Some variables were considered redundant, such as for example self-rated health, variables on prenatal diagnosis, educational level and country of birth.		Manual registration of data in MHCR was a work task assigned for midwives in ANC. The work task was not specifically indicated as more burdensome then other administrative work tasks.
The Maternal Health Care Register: use of outcome data	Most of the variables in MHCR demonstrated good to very good degree of coverage of data, agreement and internal validity. Hence, data may be regarded as reliable when used for evaluation, planning and decision-making in ANC, as well as for research purposes.	Using outcome data in operational planning in daily work was mainly reported by midwives engaged in supervision. Four out of ten midwives questioned the benefit of the MHCR.	Data comprising in total 284,789 women, and their offspring. The coverage was during 2011, 2012 and 2013 81%, 85% and 89%, respectively. The coverage of data in respective county (N=21) varied from 74% to 99%.	MHCR data were reported useful by the two participants engaged in supervision (working as heads) at their respective ANC unit. Comparing data related to own ANC clinic with data on regional level or national level, was described as the most interesting aspect.
Midwives work situation at ANC: supportive factors		MHCR was valued as helpful in the clinical work by 24.0% of the midwives with patient-related work exclusively. The corresponding figure for midwives engaged in supervision was 62.4%. MHCR was valued helpful in the administrative work by 66.0% of the midwives engaged in supervision.		Working as an ANC midwife was generally perceived positively and rewarding. Factors underpinning the work were local guidelines, continuing education, support from other professionals in the chain of care of the pregnant woman and a certain amount of autonomy. Work load was perceived high although manageable.
Midwives work situation at ANC: straining factors		To register data in MHCR was perceived as burdensome and time consuming, and a works task that someone else could perform. A direct electronic transferral of data from the medical records to the register was requested.	Six of the 21 counties in Sweden offered CUB test to all pregnant women.	The administrative work load was reported strenuous. Assistants conducting work tasks not requiring the skills of a midwife was requested.
Prenatal diagnosis	Variables on prenatal diagnosis demonstrated a coverage in MHCR varying between 90.0% to 90.1%. Agreement between data in the medical records and MHCR varied between 87.4% to 98.9%.	Variables on prenatal diagnosis were perceived as unnecessary by some participants.	Offers on prenatal diagnosis varied considerably between the 21 counties in Sweden. During 2013, uptake of CUB varied between from 2.2% to 80.3% in different counties. Advanced maternal age and educational level, university was associated with an increased OR for CUB.	Informing expectant parents on prenatal diagnosis was perceived as challenging, especially informing parents with no or limited pre-understanding. Prenatal diagnosis was described as ethically difficult to comprehend, sometimes in conflict with own values. The perceived increased focus on prenatal diagnosis, by the health care system as well as by expecting parents, was questioned.

DISCUSSION

Assuring validity in registers is essential for data to be useful in quality improvement of health care, for research as well as for administrative tasks. Methods used in investigating quality of register data depend on type of data included in the register and the medical area (107-109). Internal validity of the MHCR was investigated by comparing data registered in the medical records with corresponding data in the Swedish Maternal Health Care Register on 878 pregnancies. Information registered in the medical records was regarded as the gold standard (Paper I). Some variables registered in the MHCR are not items in the medical records so they could not be investigated. The results revealed a sufficient degree of coverage of data as well as a good to very good agreement of data in the two data sources for most variables. The Swedish Medical Birth Register (MBR) has been collecting data from the medical records since 1973 (10), and previous studies have found that most variables in the medical records and the MBR presents a sufficient degree of coverage (110, 111). Quality of different modes of data collection for the MBR has been investigated previously (110). The most recent study evaluating data in the MBR were performed in 2003, shows missing information on smoking in late pregnancy in 4-9% of the cases (111). In our study, information on the corresponding variable demonstrated a somewhat higher degree of coverage in the MHCR (99.8%) compared to the content in the medical records (97.7%). Other variables showing a higher degree of coverage in the MHCR compared to the medical records were the CUB, estimated date of delivery by ultrasound, oral glucose tolerance test performed, and two-hour value of plasma glucose at OGTT. Missing data in the medical records is most likely due to the design of the medical records as data may be registered in different forms (e.g., a form for prenatal diagnosis, a different form for laboratory data, and free text form for some variables). In comparison between the primary collection and the re-collection of data from the medical records, the variable CUB still demonstrated a higher degree of coverage in MHCR than in medical records. Variables demonstrating a lower degree of coverage in the MHCR compared to the medical record included variables on prenatal diagnosis (with the exception of the CUB). Seventeen out of the 27 investigated variables reached an agreement of data in both data sources of 95% or more. However, no variable presented identical information in all of the cases. In the re-collection of data, agreement increased and eight out of the 27 variables demonstrated identical information in both data sources in all cases (e.g., the variables on AC and CVS). This agreement may imply that the validity in MHCR data was better than demonstrated in the primary data collection. The primary data collection was performed by secretaries at each hospital, and the re-collection of data was performed by two of the authors of the study (KP, IH), both with extensive ANC experience. The nine included hospitals in the study used the software

program Obstetrix®, Siemens. During the study period, two other software programs were used in clinical practice in four of the 21 Swedish counties. These counties accounted for approximately 10% of all births in Sweden. These hospitals were not included in the present study. Between 2011 and 2013, the national uptake of the invasive prenatal methods CVS and AC were 1.1% and 2.6%, respectively. In the re-collection of data, identical information in the medical records and the MHCR was 100% for both variables CVS and AC, a finding that indicates that these figures are most likely fairly reliable. During the same period, the national uptake of CUB was 33.0%. The coverage of the variable CUB was in fact higher in the MHCR than in the medical records. The design of the medical records, not including a check box to mark if the pregnant woman has undergone CUB, may explain the lower figure for uptake of CUB in data from the medical records. Association analysis – i.e., logistic regression analysis – was performed on uptake of CUB in relation to background characteristics of the participants such as educational level, counselling due to fear of childbirth, and psychiatric disorder. The quality of these three variables was not previously investigated in Paper I. Results in Paper III showed that 7.6% of the pregnant women received counselling due to fear of childbirth and 6.3% were treated for psychiatric disorder during the index pregnancy. The variable "fear of childbirth" included in MHCR assumes a referral by a professional for counselling. In a previous study, severe fear of childbirth was estimated to be 6-11% (112). Prevalence of depression during pregnancy varies in different studies from 5% to 12% (113-116). Data in Statistics Sweden on educational level for women 25 to 44 years of age reveals similar figures on educational level distribution as MHCR, i.e. in Paper III (117), indicating that the figures on these variables in the MHCR are fairly close to results in other studies.

Midwives' work situation

The participants reported that their work as an ANC midwife brought them joy. Specifically, the midwives found professional and personal satisfaction in their encounters with women of different ages including following these women through their whole fertile life and later in life (Paper IV). Similarly, previous studies have found that midwives in primary health care reported high work satisfaction (96, 118). Not surprisingly, being older with long work experience seems to be a contributing factor to work satisfaction, a finding confirmed in Paper IV as well as in other studies (96, 119). Autonomy is reported as a primary predictor for job satisfaction (118, 120) and midwives in primary care have a greater sense of control and flexibility than hospital-based midwives presumably due to their scheduled appointments and defined caseloads (96). Our study reveals similar findings (Paper IV). Furthermore, to be an experienced ANC midwife was perceived as an advantage to better

control the work situation and more fully understand the mission of ANC (Paper IV). A series on midwifery published in Lancet in 2014 reports that "midwives were most effective when integrated into the health system in the context of effective teamwork, referral mechanisms, and sufficient resources" (121). When assessing work satisfaction among Swedish midwives, the relationship between the midwife and the physician is highly valued (96). Teamwork with colleagues (118) and collaboration in the chain of care for pregnant women was valued as supportive (Paper IV). In our study, the overall work load in antenatal care was perceived as high, although manageable, which may reflect that resources were sufficient in regard to the number of patients under surveillance (Paper IV). However, the administrative work load was considered strenuous overall. To enter identical patient data in different software programs (e.g., not one single electronic medical record including all data on a patient) was seen as unnecessary (Paper II) and potentially contributing to incorrect registration of data, placing patients at unnecessary risk (Paper IV). Entering data in the MHCR was also perceived burdensome (Paper II), although not pointed out as specifically demanding in relation to other administrative work tasks (Paper IV). The findings in Paper IV differed from the previous findings in Paper II. This difference might, at least in part, be explained by the fact that three years passed between the two data collections for Paper II and Paper IV. During this period, midwives gained more experience using the web-application for the MHCR and the software programme was also improved. Additionally, from March 2015 the amount of variables to be registered manually decreased due to automatic transferral of data. The high degree of coverage and agreement of data in the MHCR compared to the medical records indicates that data registration in the MHCR although perceived as burdensome (Paper II) the midwives performed this task competently (Paper I). Other non-patient related duties were perceived as adding stress and assistants were requested to help out with work tasks not requiring the skills of a midwife in order to ease the work situation for the midwife (Paper IV). This agrees with findings in other studies exploring work conditions for nurses and midwives (118, 122).

The Swedish Maternal Health Care Register – outcome data

Quality registers within health care are mainly to be used in evaluation as well as quality improvement of health care services. The MHCR register contains data of good to very good coverage, agreement, and internal validity, so it is reliable to use when evaluating Swedish ANC services (Paper I). A concern was raised by the midwives whether the quality of data in the MHCR was sufficient (Paper II). This concern was not confirmed by the findings in Paper I. The relevance of the included variables was questioned by some participants. It was suggested that including new variables on lifestyle habits and medical issues

such as inter-current diseases would better reflect the quality in ANC services (Paper II). Not surprisingly, foremost midwives engaged in supervision reported to regularly access data from the MHCR related to their own ANC clinic (Paper II, Paper IV), and they also the questioned the benefit of the register to a much lower degree than midwives engaged in patient-related work exclusively (Paper II). The outcome data were reported useful in understanding the current situation at the ANC clinic regarding, for example, the number of surveilled pregnant women, reflecting the work load. Furthermore, the midwives reported that it was helpful to compare their local ANC data with regional and national data (Paper II and Paper IV). It was perceived positive if the senior consultant midwife (synonymous with antenatal care coordinator) kept colleagues updated on results extracted from the MHCR and conversely as negative if results were not shared. It was also expressed that data could be used to a further extent (Paper II).

Prenatal diagnosis

A possible systematic error was demonstrated for one variable related to prenatal diagnosis in the study of internal validity of the MHCR (Paper I) – i.e., the second trimester serum screening. As a consequence of the result in Paper I, the variable second trimester serum screening was removed from the MHCR 2012 (personal message). Due to the uncertain quality of the variable, it was not included in analysis in Paper III. An increase in uptake of CUB was demonstrated from 29.8% in 2011 to 36.2% in 2013 (Paper III). During the same period, the uptake of AC decreased by 1/5 and CVS increased by 1/5. This was an expected effect of the increased uptake of CUB. Similar effects were shown when CUB was introduced in Denmark (123). In our study, we could show that CUB was offered to all pregnant women in six counties, CUB was offered on indication of advanced maternal age in nine counties, and CUB was not offered in five counties. In addition to advanced maternal age, one county included the indication anxiety related to pregnancy. Consequently, the uptake of CUB in 2013 varied considerably between Swedish counties from 2.2% to 80.3% (Paper III). During 2013, primiparaous women in Sweden had a mean age of 28.5 years (124). The county demonstrating the highest uptake of CUB showed a mean age for primiparous women of 27.8 years (124) and the corresponding figure for the county with the lowest uptake was 27.2 years (124) (Paper III). University educational level was associated with a high uptake of CUB (Paper III). A concern was raised by the midwives on the inequality of offers in different areas of Sweden, and that highly educated parents were perceived as requesting prenatal diagnosis to a higher extent than parents with a lower educational level (Paper IV). Expecting parents were perceived to focus too much on prenatal diagnosis when other important aspects of the pregnancy seemed to be overlooked (Paper IV). Some participants in Study II reported

that variables in MHCR on prenatal diagnosis were redundant (Paper II). Informing expecting parents on prenatal diagnosis, especially on the CUB, was reported as a challenging work task (Paper IV). Furthermore, to inform expecting parents with varying educational levels and varying pre-understandings challenged midwives in different ways (Paper IV). A Dutch study investigating midwives' and clients' views on counselling on prenatal diagnosis finds that midwives who focus on giving information may inhibit a true dialogue with the patient because this approach can ignore individual preferences. This lack of attention to individual needs may negatively affect the goal of counselling – empowering parents to make an informed autonomous decision (125). The ability to value risk assessment depends on how the risk assessment is presented and the 1 out of 100 format incites a higher perceived risk than when presented in the 10 out of 1000 format (126) this finding is generally applicable when discussing medical risks with patients (127).

Methodological considerations

This thesis has its strengths and limitations. Study I investigated the internal validity of the Swedish Maternal Health Care Register and was performed in two steps: a primary investigation of data quality in the MHCR compared to data in the medical records and a secondary step investigating quality of the data registration of the primary data collection. Data were collected from nine hospitals in Sweden varying in level of health care, birth volumes, and demography. In our study, background characteristics on maternal age and BMI were very similar to data in the MHCR as well as in the Medical Birth Register for 2011, indicating that the study sample was representative for the year under study (54).

In Study II, all ANC midwives working in Sweden at the time of the study were addressed. The estimated number of ANC midwives was 1,863 and 989 of these responded to the questionnaire, resulting in an overall response rate of 53.1%. During the data collection period, some midwives may have been absent from work, so the actual response rate might have been somewhat higher than the calculated proportion. It is essential to put a great deal of effort in constructing a questionnaire to obtain relevant and useful information (128). The questionnaire used in Paper II consisted of background characteristics of the participants, pre-formed statements, and open-ended questions. The questionnaire was composed by the authors of Paper II. All authors but one had an engagement in the MHCR and had work experience with an ANC, including many encounters with midwives. The familiarity with the topic was essential for the construction of the questionnaire, but pre-understanding might also have resulted in exclusion of important questions. We aimed for as honest replies as possible, therefore we decided that the questionnaire would be responded anonymously, to assure anonymity of the participants, measures

were taken in regard to how the responded questionnaire was sent back to the researchers. These measures for securing anonymity might have aggravated the procedure, decreasing the response rate. Due to this procedure, evaluation of non-respondents was limited. The mean age of the participants in Study II was fairly close to official data on midwives (129) (i.e., the participants were most probably representative for the group). Study III used data from the MHCR that had previously been investigated in Study I and demonstrated sufficient internal validity. Another strength of Study III was the large sample size comprising 284,789 women and their offspring. In addition, the guidelines regarding offers to pregnant women on prenatal screening and diagnostic procedures were collected from all MHCA (N=43) in Sweden for 2011, 2012, and 2013. In analysis on background characteristics in relation to uptake of prenatal diagnosis data from the MHCR was used. The validity for some of the used variables was not investigated in Study I. In addition, we cannot rule out that other determinants not registered in the MHCR may have affected the uptake of prenatal diagnosis.

In Study IV, we aimed to ensure trustworthiness by applying the following components of qualitative research: credibility, transferability, dependability, and confirmability (104). Credibility was sought by recruiting participants using purposive sampling to capture a variety of perspectives and experiences by participants from different settings. Consistency in data collection and analysis was sought by a semi-structured interview guide used for all interviews, including key domains and open questions on perspectives about ANC. The first author (KP) performed all interviews over 12 months, a strategy that increased dependability. To ensure transferability, data were collected until saturation of data was assessed being achieved. Confirmability was sought by discussing the results within the research team, all experienced in ANC but from different professional perspectives, challenging pre-understanding of the subject under study. A possible limitation of Study IV was that suggestions of eligible participants were obtained from the ACC. It cannot be excluded that eligible participants were chosen by some other criteria than determined by the study design. Additionally, the first author (KP) was engaged in the SPR during the study period, which might have biased the participants when expressing opinions on the SPR. We cannot exclude that significant aspects of ANC might have been overlooked in the interviews.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Data in the Swedish Maternal Health Care Register demonstrated sufficient quality and is reliable to use in evaluation of ANC services as well as for research purposes. Evaluating the quality in quality registers is a permanent work task. MHCR was in general valued positively although manual registration of data was reported as burdensome. The MHCR was an under-used source for operational planning and quality assessment in local ANC. Midwives generally enjoyed their work in antenatal care. They appreciated the collaboration between professionals in the chain of health care for pregnant women. Clinical guidelines and continuing education were considered essential in providing good quality and evidence-based health care. The administrative work was perceived to be strenuous, and some participants felt that some of their administrative work tasks could be performed by others. Inter-operability between IT-systems can reduce the administrative work tasks. Offers of prenatal diagnosis varied considerably between counties in Sweden. Maternal age and educational level demonstrated strong associations with uptake of prenatal diagnosis. Informing about prenatal diagnosis was perceived as challenging, especially when the expecting parents had no or limited pre-understanding. These circumstances could result in an unequal access of prenatal diagnosis for expecting parents. Pedagogical tools that provide intelligible information to expecting parents with varying pre-understanding may facilitate this mission. All expecting parents in Sweden should be offered the same opportunities on prenatal diagnosis.

FUTURE RESEARCH

- Investigate validity of data included in the Swedish Pregnancy Register captured by direct electronic transferral of data from medical records to SPR.
- Explore factors related to health care services' use of SPR data in operational evaluation and improvement.

Personal notes

"If you stop improving – you stop doing a good work" was the title of a report that two midwives published on quality assurance in primary health care in the mid-1990s (130). At that time, I was busy learning the skills of midwifery – how to become a competent, respectful, listening person with warm and confident hands. I did not pay much attention to their report then, but somehow the sentence stuck in my mind. Ten years later, when I got involved in the Swedish Maternal Health Care Register (MHCR), I thought about the report and the title began to make more sense. There is always a potential for improvement in health care. "You can only measure what you can measure" is another sentence that comes into my mind every now and then. This expression may be obvious and mundane, yet it is important to remember when it comes to evaluating preventive work in public health care based on counselling on lifestyle habits. In a wide societal perspective, many uncontrollable factors influence our habits and how we live our lives. It is not always possible to assess the impact of a single intervention as preventive work in the public health arena because this work includes many actors and the outcome of interventions might take many years. During my mid-term seminar, I was asked this question: "What is the red thread in your thesis"? I have given this question a lot of thought and the answer is that there is not one single thread, but three threads very tightly intertwined. The first is the Swedish Maternal Health Care Register (MHCR) – a tool for quality assessment and improvement of antenatal care. The second thread is the work situation of midwives in antenatal care. And the third thread is prenatal diagnosis. All three threads are in some way investigated in each of the included studies. Fundamentally, my involvement in the register was the reason why I was invited to do research as a doctoral candidate – an invitation for which I'm truly grateful. Some offers you can't refuse.

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APPENDIX 1 Questionnaire, Study II (in Swedish)

Mödrahälsovårdsregistret – enkätstudie (MHV-område 1)

BAKGRUNDSFRÅGOR

1. Arbetar du som:

☐ Barnmorska med patientarbete

☐ Barnmorska i arbetsledande funktion

☐ Barnmorska med patientarbete och arbetsledande funktion

2. Ange din ålder (år):

.....

3. Hur länge har du arbetat som barnmorska (år)?

.....

4. Hur länge har du arbetat inom mödrahälsovård (år)?

.....

5. Vilken är din aktuella sysselsättningsgrad (som barnmorska inom mödrahälsovård):

☐ < 50%

☐ 50-75%

☐ > 75%

6. Ange vilken typ av mottagning du arbetar på:

☐ Mottagning - privat

☐ Mottagning – landsting

7. Hur många gravida träffar du en normal arbetsvecka?

.....

8. Jag registrerar uppgifter i MHV-registret

☐ Dagligen

☐ Flera gånger i veckan

☐ En gång per vecka

☐ Några gånger varje månad

☐ Mer sällan

Följande frågor gäller MHV-registrets startsida – dvs. den första sidan som du får upp innan du loggar in dig för att registrera data

Ta ställning till följande påståenden och kryssa i lämpligt alternativ!

9. Det är lätt att få överblick

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

10. Det är lätt att orientera sig

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

11. Startsidans layout är tilltalande för ögat

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

12. Färgerna är tilltalande för ögat

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

13.Textens typsnitt är lätt att läsa

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

14. Texten är lätt att förstå

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

15. Textstorleken fungerar väl

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

16. Jag får den information jag behöver om registret

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

17. Tacksam för **Dina** eventuella kommentarer avseende hur startsidan kan förbättras:

.....

.....

Följande frågor gäller MHV-registrets användarmanual

18. Har du läst MHV-registrets användarmanual?

☐ Ja – fortsätt med fråga 19.

☐ Nej – gå till fråga 22.

Om du har läst användarmanualen – ta ställning till följande påståenden och kryssa i lämpligt svar:

19. Texten är formulerad på ett lättförståeligt sätt

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

20. Manualen gav mig den information som jag behövde

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

21. Tacksam för **Dina** eventuella kommentarer om hur manualen kan förbättras:

.....

.....

Följande frågor gäller registrering av uppgifter

Ta ställning till följande påstående och kryssa i lämpligt svar:

22. Programvaran är utformad så att det är lätt att registrera uppgifter

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

23. Tacksam för **Dina** eventuella kommentarer/förslag till förbättring av registrering av uppgifter:

.....

.....

Följande frågor gäller inskrivningsdelen

Ta ställning till följande påståenden och kryssa i lämpligt alternativ:

24. Frågorna i inskrivningsdelen är lätta att förstå

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

25. Frågorna i inskrivningsdelen kommer i en logisk ordning

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

26. Tacksam för **Dina** eventuella kommentarer om hur ordningen av frågorna kan förbättras:

.....

.....

27. Finns det andra frågor som du anser borde ingå i inskrivningsdelen?

☐ Ja – fortsätt till fråga 28.

☐ Nej – fortsätt till fråga 29.

28. Om du anser att andra frågor bör ingå i inskrivningsdelen är vi tacksamma om du ger exempel på sådana frågor:

.....

.....

29. Finns det frågor i inskrivningsdelen som du upplever är onödiga?

☐ Ja – fortsätt till fråga 30.

☐ Nej – fortsätt till fråga 31.

30. Om du anser att frågor i inskrivningsdelen är onödiga är vi tackamma om du ger exempel på sådana frågor:

.....

.....

Följande frågor gäller uppföljningsdelen

Ta ställning till följande påståenden och kryssa i lämpligt alternativ:

31. Frågorna i uppföljningsdelen är lätta att förstå

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

32. Frågorna i uppföljningsdelen kommer i en logisk ordning

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

33. Tacksam för **Dina** eventuella kommentarer om hur ordningen av frågorna kan förbättras:

.....

.....

34. Finns det andra frågor som du anser borde ingå i uppföljningsdelen?

☐ Ja – fortsätt till fråga 35.

☐ Nej – fortsätt till fråga 36.

35. Om du anser att det finns frågor som borde ingå i uppföljningsdelen är vi tacksamma om du kan ge exempel på sådana frågor:

.....

.....

36. Finns det frågor i uppföljningsdelen som du upplever är onödiga?

☐ Ja – fortsätt till fråga 37.

☐ Nej – fortsätt till fråga 38.

37. Om du anser att det finns frågor i uppföljningsdelen som är onödiga är vi tacksamma om du ger exempel på sådana frågor:

.....

.....

Följande frågor gäller påminnelsefunktionen

38. Hur ofta använder Du påminnelsefunktionen i registret?

☐ Regelbundet

☐ Sällan

☐ Inte alls

39. Tacksam för **Dina** eventuella kommentarer om hur påminnelsefunktionen kan förbättras:

.....

.....

Följande frågor gäller Dig som **INTE** har en arbetsledande funktion
(Om du har en arbetsledande funktion – fortsätt till fråga 46)

Ta ställning till följande påståenden och kryssa i lämpligt alternativ:

40. Jag hämtar regelbundet ut information från MHV-registret avseende mottagningens gravida (rapportfunktionen)

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

41. Jag tycker att MHV-registret är till hjälp i mitt arbete

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

42. Jag tycker att MHV-registret är en belastande arbetsuppgift

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

43. Jag får en bättre sammanhållen bild av den gravida kvinnan (vid inskrivningsregistrering) genom att föra in uppgifter i registret

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

44. Jag ifrågasätter nyttan av att föra in uppgifter i MHV-registret

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

45. Vilka frågor tycker du är mest intressanta att ta fram rapporter på?

.....

.....

8

Följande frågor gäller Dig som **HAR** en arbetsledande funktion
(Du som inte har en arbetsledande funktion – fortsätt till fråga 62)

Ta ställning till följande påståenden och kryssa i lämpligt svar:

46. Jag hämtar regelbundet ut information från MHV-registret avseende mottagningens gravida (rapportfunktionen)

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

47. Jag tycker att MHV-registret är till hjälp i mitt patientarbete

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

48. Jag tycker att MHV-registret är till hjälp i mitt administrativa arbete

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

49. Jag tycker att MHV-registret är en belastande arbetsuppgift

(0=instämmer inte alls och 5= instämmer helt)

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej

50. Jag får en bättre sammanhållen bild av den gravida kvinnan (vid inskrivningsregistrering) när jag för in uppgifter i MHV-registret

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

51. Jag använder data från MHV-registret i min verksamhetsplanering

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

52. Jag använder data från MHV-registret som underlag för ekonomiska beslut

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

53. Jag använder data från MHV-registret för att beskriva mottagningens vårdtyngd

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

54. Jag använder data från MHV-registret från min mottagning och jämför med andra nivåer (MHV-område, landsting, riket)

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

55. Jag presenterar data från MHV-registret för mina medarbetare på mottagningen

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

56. Jag upplever att mina medarbetare är intresserade av mottagningens data

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

57. Jag vidarebefordrar/presenterar data från MHV-registret till mina chefer

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

58. Jag vidarebefordrar/presenterar data från MHV-registret till landstingets Forsknings- och utvecklingsenhet (eller motsvarande)

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

59. Jag vidarebefordrar/presenterar data från MHV-registret till annan nivå (ange organisation).....

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

60. Jag ifrågasätter nyttan av att föra in uppgifter i MHV-registret

☐ ☐ ☐ ☐ ☐ ☐ ☐
0 1 2 3 4 5 ingen åsikt/vet ej
(0=instämmer inte alls och 5= instämmer helt)

61. Om du använder data från MHV-registret i ett annat sammanhang, vänligen beskriv kortfattat!

.....

.....

På följande fråga kan du lämna ytterligare synpunkter och kommentarer

62. Här kan du lämna ytterligare synpunkter och kommentarer på MHV-registret:

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

TACK FÖR DIN MEDVERKAN!

APPENDIX 2 Interview guide, Study IV (in English)

Table 1. Key domains in the interview guide

The midwives´ experiences/views on:

WORK SITUATION
- Overall work situation
- Supportive factors
- Straining factors

PRENATAL DIAGNOSIS
- Informing expecting parents
- Knowledge on prenatal diagnosis in relation to demands

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Internal validity of the Swedish Maternal Health Care Register

Kerstin Petersson[1*†], Margareta Persson[2], Marie Lindkvist[3], Margareta Hammarström[4], Carin Nilses[5], Ingrid Haglund[6], Yvonne Skogsdal[7] and Ingrid Mogren[1†]

Abstract

Background: The Swedish Maternal Health Care Register (MHCR) is a national quality register that has been collecting pregnancy, delivery, and postpartum data since 1999. A substantial revision of the MHCR resulted in a Web-based version of the register in 2010. Although MHCR provides data for health care services and research, the validity of the MHCR data has not been evaluated. This study investigated degree of coverage and internal validity of specific variables in the MHCR and identified possible systematic errors.

Methods: This cross-sectional observational study compared pregnancy and delivery data in medical records with corresponding data in the MHCR. The medical record was considered the gold standard. The medical records from nine Swedish hospitals were selected for data extraction. This study compared data from 878 women registered in both medical records and in the MHCR. To evaluate the quality of the initial data extraction, a second data extraction of 150 medical records was performed. Statistical analyses were performed for degree of coverage, agreement and correlation of data, and sensitivity and specificity.

Results: Degree of coverage of specified variables in the MHCR varied from 90.0% to 100%. Identical information in both medical records and the MHCR ranged from 71.4% to 99.7%. For more than half of the investigated variables, 95% or more of the information was identical. Sensitivity and specificity were analysed for binary variables. Probable systematic errors were identified for two variables.

Conclusions: When comparing data from medical records and data registered in the MHCR, most variables in the MHCR demonstrated good to very good degree of coverage, agreement, and internal validity. Hence, data from the MHCR may be regarded as reliable for research as well as for evaluating, planning, and decision-making with respect to Swedish maternal health care services.

Keywords: Validity, Degree of coverage, National quality register, Medical records, Pregnancy outcomes, Antenatal care

Background

Health data registers and quality registers

Nordic countries have a long tradition of using population-based health data registers to monitor the general population. These health data registers include the Swedish Cause of Death Cause Register (1952), the Swedish Cancer Register (1958), the Norwegian Medical Birth Register (1967), and the Swedish Medical Birth Register (1973) [1]. Swedish health data registers are regulated by the Health Data Law in the Swedish code of statues (1998:543) and it is compulsory for patients, as well as for the health care services, to participate in these registers [2]. The health data registers use standardized data collection procedures, enabling surveillance of the health status of the population [3]. In addition, these registers are available to researchers [3-6]. Over the last several decades, a growing number of national quality registers surveying specific medical areas have been established in Sweden. Quality registers have been initiated and are administered by professional associations from different medical areas. In contrast to health data registers, participation in quality registers is voluntary for both patients and health care providers. That is, patients can choose not to contribute their individual data to a quality register. Quality registers are regulated by the

* Correspondence: kerstin.petersson@sodersjukhuset.se
†Equal contributors
[1]Department of Clinical Sciences, Obstetrics and Gynecology, Umeå University, Umeå, Sweden
Full list of author information is available at the end of the article

Swedish code of statutes (2008:355) [2]. The quality registers provide a unique possibility to survey different aspects of health care and health care outcomes. In addition, quality registers can be used to conduct research, to improve quality of health care, and to manage health care services [7]. Clearly, it is important that data in the registers are valid and representative [8]. The major part of quality registers are financed by the Swedish government and the Swedish Association of Local Authorities and Regions, government entities that have deemed it a national priority that quality registers should cover at least 80% of the population [7].

In Sweden, management of national quality registers is regulated by Swedish legislation and the National Board of Health and Welfare [7]. Collection and management of patient data in quality registers are regulated by the Swedish Patient Data Law, which charges health providers the responsibility of informing patients on the existence of a specific health register, the purpose of the register, and the type of data that are reported to the register. The patients are informed that their participation in the health register is voluntary and that removal of data is automatically granted if the patient desires [9].

The Swedish Maternal Health Care Register

The Swedish Maternal Health Care Register (MHCR) is a national quality register established in 1999. In 2007, a substantial revision was performed of its variables, Web application, and technical solutions. The revised version of MHCR was launched on January 1, 2010. The MHCR collects pregnancy, delivery, and postpartum data, including individual data on the pregnant women, foetuses, and infants. In 2010 and 2011, 81% and 85%, respectively, of the pregnant population were registered in the MHCR (personal communication). The main bulk of data registered in MHCR is related to pregnancy and delivery, but data on lifestyle, education, and socioeconomic factors are also reported. In accordance with the Swedish Patient Data Law [9], all antenatal care centres (ANC) are charged with informing each pregnant woman on the existence of the MHCR, its purpose, its content, and the fact that providing data is voluntary.

Data in the MHCR are entered on two different occasions by attending ANC midwives. Entering data into the MHCR is performed using a Web-based application specifically created for this purpose. To protect the integrity of the data, each midwife is provided with an individual user identity and a secure login procedure. The first dataset is entered when a pregnant woman registers in ANC. This dataset mainly includes information about background characteristics, such as educational level, weight, height, and smoking habits. On the first visit, Body Mass Index (BMI) is calculated using a software program built into the MHCR.

According to national recommendations for health care during pregnancy and after delivery, all women should be offered a postpartum meeting with a midwife in the ANC four to 16 weeks after delivery [10]. The second data entry takes place soon after the postpartum visit and includes items related to pregnancy, delivery, and the postpartum period. If a woman does not attend the voluntary postpartum visit, the midwife enters the second set of data at around 16 weeks postpartum using information from the medical records. The items in this second data entry address the outcomes of pregnancy and delivery.

Most of the registered items entered in the MHCR are data obtained from medical records manually registered by a midwife. The MHCR database is administrated by the Uppsala Clinical Research Centre (UCR), which specifically supports the maintenance of national quality registers and assists researchers using these registers.

No previous study has evaluated the validity of data included in the MHCR. As national quality registers are used for quality improvement and management within regional and local health care services as well as for research, it is important that the quality of data in the registers is high.

Aims

This study investigate the validity of data entered in the MHCR. The study has three specific aims: *i*) to explore degree of coverage of specified variables; *ii*) to investigate internal validity of data, including sensitivity and specificity of binary variables; and *iii*) to identify potential systematic errors.

Methods

Study design and study sample

This cross-sectional observational study compared data on pregnancy and delivery using medical records and the MHCR. The Regional Ethical Board at Umeå University (Umeå, Sweden) approved the national study (Dno 2012-44-31 M).

A power estimation was performed to determine the sample size; to obtain kappa values of 0.6 (considering the null value of kappa to be 0.4) and to achieve 90% power, a sample size of 540 was required if the prevalence was 0.1 (or 0.9) and 220 if the prevalence was 0.5. However, kappa is very sensitive to prevalence and as the categorical variables vary considerably with respect to prevalence, a sample of 900 medical records was judged to be a sufficient sample size to respond to the research questions under study. This study uses a national sample comprising nine Swedish hospitals, 100 medical records from each hospital. The hospitals were selected because they provided a variation in geographic and demographic characteristics. In Sweden, there were

109,752 deliveries in 2011. The data collection was performed at hospitals representing delivery units ranging from 1,298 to 10,363 births in 2011 [11] and covered the northern and southern regions of Sweden. To some extent, the selection of hospitals was influenced by convenience, as most of the authors of this study constituted a subset of the board of the MHCR and are affiliated with five of the selected hospitals included in the study. These circumstances provided a better opportunity to supply instructions and support to the local administrators who were extracting the data from the medical records.

Inclusion criteria for the study were medical records of women with data on pregnancy and delivery both in the medical records and in the MHCR. Exclusion criteria were data lacking in either of these two data sources.

Medical records of pregnancy, delivery, and the postpartum period

The software program Obstetrix® is widely used in Sweden and contains pregnancy, delivery, and postpartum data, accounting for approximately 90% of medical records on pregnant women in Sweden. Other software programs used in clinical practice are Partus® and Cosmic Birth®. A few clinics still document medical data using pen and paper.

Data collection procedures

Before the start of the study, the heads of all participating clinics provided verbal consent to participate. After the consent was secured from the heads of the clinics, local administrators, one administrator at each hospital, were contracted to supply the data registration. Most of the local administrators were medical secretaries, but in a few hospitals midwives or other staff were contracted.

In 2011, data on 85% of all pregnant women were included in the MHCR. Therefore, the personal identity numbers of 120 consecutively delivered women were extracted from the birth log at each clinic to ensure that 100 women were identified from each clinic with data both in the medical records and in the MHCR. From the nine clinics, we selected 100 women per clinic who gave birth from March 1st, and whose data were in their medical records and in the MHCR. The smaller clinics required a longer time to collect these data (March 1st to May 29th) and the larger clinics required a shorter time (March 1st to March 9th). Extracted data from the medical records for the 900 women were transferred in encrypted form to the UCR. The UCR combined the extracted data in the medical records with the corresponding data in the MHCR. The goal was to collect data on 100 women from each hospital; i.e., we wanted to have data from 900 medical records. For seven hospitals, data on 100 women were incomplete. Despite repeated reminders by e-mail and by telephone, no further data were delivered, resulting in a final dataset of extracted data from 878 medical records.

Study protocol

An Excel®-protocol was developed by the authors to register categorical and numeric variables extracted from the medical records and to secure that data were extracted in a similar manner at all hospitals. In general, registration of data from the medical records into the Excel®-protocol was done manually by the local administrator. However, in one hospital data were electronically collected from the medical records and imported into the Excel®-protocol. Then the content of each Excel®-protocol was encrypted and sent to the UCR.

Data from Excel®-protocols and data from the MHCR were merged by the UCR using the personal identity number for each woman. To ensure that individuals could not be identified, the merged dataset was delivered to the authors with each individual given a unique serial number.

Presentation of included variables

All variables included in the MHCR and the selected variables for this study are presented in Table 1. Some variables available in the MHCR were excluded for the validity control, such as variables regarding the postpartum period and variables with no corresponding data in the medical records (e.g., the variables of self-reported health before, during, and after pregnancy).

Most of the categorical variables in the MHCR had the response options of "yes", "no", or "don't know". However, two variables had other response options: "mode of delivery" ("caesarean section", "instrumental vaginal delivery", or "non-instrumental vaginal delivery") and the variable "gender" ("girl", "boy", or "unknown gender"). Three of the categorical variables with response options "yes", "no", or "don't know" had an additional question if the response "yes" was noted. These variables had the following additional options: *i*) Alcohol Use Disorder Identification Test (AUDIT) scores; *ii)* the options elective caesarean section (CS) or emergency CS, if mode of delivery was registered as CS; and *iii)* the two-hour plasma glucose value was requested if an oral glucose tolerance test (OGTT) had been performed.

Quantitative variables were registered as continuous numeric values. Birth weight was registered in grams. Maternal body weight was recorded in whole kilograms and maternal height in centimetres. AUDIT-scores ranged from 0 to 40. Variables addressing dates were registered in a pre-set calendar format. Some deliveries were multiple births. Data on first twin, such as mean birth weight and mode of delivery, were included in the presentation of singleton pregnancies. Mean birth weight for second twin was also calculated.

Table 1 Presentation of all variables registered at first and second data entry in the Swedish Maternal Health Care Register (MHCR)

First data entry	Second data entry	
Data collected at first visit in antenatal care (ANC)	**Data collected at postpartum visit in antenatal care (ANC) 4 to 16 weeks after delivery**	
Variables	**Variables**	**Variables**
Date of first visit in ANC[a]	**Live born child**	Treatment of psychiatric disorder
Country of birth	Still birth/termination of pregnancy	Questioned about exposure to violence
No. of previous deliveries	Date of delivery estimated by ultrasound	**Oral glucose tolerance test (OGTT) performed**
Maternal weight (kilograms)[b]	**Estimated date of delivery (ultrasound)**	**2-hour value of plasma glucose at OGTT (mmol/L)**
Maternal height (centimetres)[b]	Estimated date of delivery (last menstruation)	Diagnosis of gestational diabetes mellitus (GDM)
Smoking three months prior to pregnancy	**Ultrasound examination at gestational age 16-21 week**	**Date of delivery**
No. of cigarettes/day three months prior to pregnancy	**Combined Ultrasound and Biochemical screening (CUB)**	Maternal age at delivery
Smoking at first ANC visit	**Second trimester serum screening**	**Mode of delivery**
No. of cigarettes/day at first ANC visit	**Chorionic villus sampling (CVS)**	**If caesarean section, elective or emergency section**
Use of snuff three months prior to pregnancy	**Amniocentesis (AC)**	**Singleton birth/multiple births**
Use of snuff at first ANC visit	**Number of antenatal visits until estimated date of delivery (determined by ultrasound)**	**Birth weight (grams)[c, d]**
Assessment of use of alcohol prior to pregnancy with screening instrument Alcohol Use Disorder Identification Test (AUDIT)	Number of midwives surveying the pregnant woman in ANC	**Gender of infant[d]**
AUDIT-score	Use of authorized interpreter	Documented suspicion of intrauterine growth retardation
Education level	**Smoking at 32 weeks of gestation**	Postpartum visit at ANC
Employment status	No. of cigarettes/day at 32 gestational weeks	Date of postpartum visit at ANC
Self-rated health prior to pregnancy	**Use of snuff at 32 weeks of gestation**	Maternal body weight at postpartum visit at ANC (kilograms)
	Maternal weight (in kilograms), last data entry after 35 gestational weeks	Self-rated health during pregnancy
	Participated in prenatal education group (pregnant woman)	Self-rated health postpartum
	Participated in prenatal education group (partner)	Breast feeding at 4 weeks postpartum
	Counselling due to fear of childbirth	

Variables presented in bold text were selected for the comparison of data in medical records and in MHCR.
[a]Gestational age at registration in ANC is calculated by the software program.
[b]Body Mass Index (BMI) at registration in ANC is calculated by the software program.
[c]Foetal growth proportionality – i.e., appropriate for gestational age (AGA), large for gestational age (LGA), and small for gestational age (SGA) – is calculated by the software program.
[d]In cases of multiple births, birth weight and gender are also registered for second twin.

Control of data registered in the protocol

To investigate to what extent data from the medical records had been correctly registered in the Excel®-protocol, a second data extraction was performed (i.e., re-collection of data). Three of the participating hospitals – Östersund Hospital (Östersund), Södersjukhuset (Stockholm), and Umeå University Hospital (Umeå) – were selected for this control procedure. Two of the authors (KP and IH, both midwives with extensive experience with ANC) performed this re-collection of data. An identical Excel®-protocol as used for the first data collection from medical records was used for this second data collection procedure. The goal was to include every second woman from the primary dataset from each of the three selected hospitals in this second validation procedure of data (i.e., data were collected from medical records on 50 women from each hospital, resulting in data from 150 medical records).

Statistical analysis

Data from the medical records were considered the gold standard. The proportions of available data in the medical records and in the MHCR and the proportions of data available in both data sources were calculated for each variable. In addition, the proportion of cases where the medical records and the MHCR presented identical information was calculated for each variable. For the subset of data (re-collected dataset) where the categorical variables with a subsequent explorative question in the case of a "yes" response, the number of "yes" responses constituted the denominator in the calculations. Degree of agreement was estimated using Cohen's kappa for categorical data and Pearson's correlation coefficient was used for normally distributed, continuous data. Spearman's correlation coefficient was used to evaluate dates. Sensitivity and specificity were analysed for binary variables. Sensitivity was defined as the proportion of actual positives, that were correctly identified as such. Specificity was defined as the proportion of negatives that were correctly identified as such. Sensitivity and specificity were analysed for binary variables. SPSS version 19 was used for all calculations. The level of significance was set at 0.05.

Results

Background presentation

Corresponding data on pregnancy and delivery from medical records and the MHCR were collected from 878 medical records at nine hospitals. These hospitals and their characteristics are presented in Table 2. The number of deliveries at the included hospitals corresponds to 28.0% of the total number of deliveries in Sweden in 2011. The data collected from medical records included mean age (30.7 years, SD ±5.0), mean BMI (24.6, SD ±4.6), and mean birthweight of infant (3515 g, SD ± 568). Eleven pregnancies were multiple births. The mean gestational age was 278.2 days (SD ±12.5) or 39.7 weeks (SD ±1.8) for singleton births and 241.6 days (SD ±36.2) or 34.5 weeks (SD ±5.2) for multiple births. Mean birth weight of second twin was 1810 g (SD ±1003).

Degree of coverage of data in medical records and in the MHCR

The degree of coverage of all investigated variables is presented in Table 3. The degree of coverage of variables included in medical records varied from 48% to 100% and most variables presented high degree of coverage in medical records. There was a high degree of coverage for the categorical variable OGTT (98.9%) in medical records. However, there was a lower degree of coverage for the associated variable "OGTT two-hour value of plasma glucose" (48.0%) in medical records.

Degree of coverage of data registered in the MHCR varied between 90.0% and 100%. The variables with a relatively lower degree of coverage in the MHCR, although in fact a high degree of coverage, addressed various forms of prenatal diagnostics with a degree of coverage of approximately 90%.

Data available in both data sources (medical records and MHCR) ranged from 46.0% to 100%. Variables with complete data in both data sources were variables addressing date of birth and whether the child was born alive or stillborn. Other variables with a high level of data available in both data sources included "singleton birth/multiple births" (99.8%), "mode of delivery" (99.5%), and "gender of child" (99.5%).

Table 2 Characteristics of the nine participating hospitals and number of medical records extracted at each hospital

City	Participating hospital	Level of health care	Inhabitants/ km^2 2011[a]	No. of births 2011[b] (%)[c]	No. of medical records (%)[d]
Göteborg	Sahlgrenska University Hospital	University	66.8	10363 (9.4)	91 (10.4)
Halmstad	Halmstad Hospital	County	55.6	1799 (1.6)	96 (10.9)
Jönköping	Ryhov Hospital	County	32.4	2075 (1.9)	99 (11.3)
Stockholm	Karolinska University Hospital	University	320.5	4642 (4.2)	96 (10.9)
Stockholm	Södersjukhuset	University	320.5	7331 (6.7)	98 (11.2)
Sundsvall	Sundsvall Hospital	Regional	11.2	1536 (1.4)	100 (11.4)
Umeå	Umeå University Hospital	University	4.7	1817 (1.6)	100 (11.4)
Örebro	Örebro University Hospital	University	33.1	2867 (2.6)	99 (11.3)
Östersund	Östersund Hospital	Regional	2.6	1298 (1.2)	99 (11.3)
				30728 (28.0)	878 (100%)

[a]Population density in catchment area. Data from "Inhabitants per kilometer^2" [Internet] Statistics Sweden; 2011 (cited 2013, June 6) http://www.scb.se/Pages/SSD/SSD_SelectVariables340487.aspx?px_tableid = ssd_extern%3aBefArealTathetKon&rxid = ca8cabdd-0d60-488b-b047-4b5c5a89dcb5.
[b]Data from National Board of Health and Welfare'Graviditeter, förlossningar och nyfödda barn. Medicinska Födelseregistret 1973-2011. Assisterad befruktning 1991 – 2010' [in Swedish] http://www.socialstyrelsen.se/publikationer2013/2013-3-27.
[c]Proportions are calculated by using the total no of births in Sweden 2011 (N = 109 752) as denominator.
[d]Proportions are calculated by using the total no of medical records as denominator.

Table 3 Data in medical records and the Sweedish Maternal Health Care Register (MHCR); comparison between the two data-sets using correlation analysis, and analysis of sensitivity and specificity for binary variables

Variable	Data source: Medical records		Data source: MHCR		Data available in both data sources		Identical information in both data sources		Correlation[a]	Sensitivity	Specificity
	n	%	n	%	n	%	n	%			
Variables collected at first antenatal care (ANC) visit											
Date of first visit in ANC (numerical)	877	99.9	868	98.9	867	98.7	685	79.0	0.878 (S)		
No of previous deliveries (numerical)	878	100	867	98.7	867	98.7	840	96.8	0.971 (P)		
Maternal weight at first ANC visit (numerical)	862	98.1	855	97.4	847	96.4	798	94.2	0.990 (P)		
Maternal height (numerical)	872	99.3	862	98.2	860	97.9	834	97.0	0.982 (P)		
Smoking at first ANC visit (Yes/No)	875	99.7	872	99.2	868	98.9	843	97.1	0.742 (C)	0.650	0.995
Use of Snuff at first ANC visit (Yes/No)	878	100	871	99.2	871	99.2	861	98.9	0.540 (C)	0.429	0.998
Assessment of alcohol screening prior to pregnancy (AUDIT) (Yes/No)	802	91.3	859	97.8	788	89.7	691	87.7	0.480 (C)	0.986	0.393
If Yes, AUDIT score (numerical)[b]	650/643	98.9	777/771	99.2	621	95.5	600	96.6	0.989 (P)		
Variables collected at 4 to 16 weeks postpartum											
Prenatal diagnostics											
Amniocentesis (AC) (Yes/No)	875	99.7	791	90.1	788	89.7	772	98.0	0.754 (C)	0.743	0.991
Chorion Villus Sampling (CVS) (Yes/No)	875	99.7	790	90.0	787	89.6	778	98.9	0.176 (C)	0.167	0.995
Combined Ultrasound and Biochemical screening (CUB) (Yes/No)	780	88.8	791	90.1	700	89.7	665	95.1	0.888 (C)	0.936	0.957
Second trimester Serum Screening (Yes/No)	849	96.7	790	90.0	767	87.4	671	87.4	0.002 (C)	0.043	0.958
Ultrasound examination at 16 – 21 gestational weeks (Yes/No)	862	98.2	791	90.1	779	88.6	755	96.9	0.064 (C)	0.979	0.800
Estimated date of delivery (ultrasound) (numerical)[c]	871	99.2	874	99.5	868	98.9	781	90.0	0.946 (S)		
Oral Glucose Tolerance Test (OGTT) performed (Yes/No)	869	98.9	877	99.9	868	98.9	842	97.0	0.854 (C)	0.880	0.982
If Yes, 2-hour value of plasma glucose at OGTT (numerical)[d]	100/48	48.0	104/97	93.3	46	46.0	34	73.9	0.902 (P)		
Smoking at 32 gestational weeks (Yes/No)	858	97.7	876	99.8	856	97.5	849	99.1	0.864 (C)	0.821	0.998
Use of Snuff at 32 gestational weeks (Yes/No)	832	94.8	876	99.8	830	94.5	826	99.5	0.712 (C)	0.625	0.999
Maternal weight, last data entry after 35 gestational weeks (numerical)	777	88.5	843	96.0	760	86.6	706	92.9	0.989 (P)		
No. of ANC visits until estimated date of delivery (numerical)	877	99.9	868	98.9	867	98.7	627	72.3	0.915 (P)		
Date of delivery (numerical)	878	100	878	100	878	100	842	95.9	0.989 (S)		
Live born child (Yes/No)	878	100	878	100	878	100	874	99,5	0.598 (C)	0.999	0.500
Birth weight (numerical)	876	99.8	869	99.0	868	98.9	813	93.7	0.989 (P)		

Table 3 Data in medical records and the Sweedish Maternal Health Care Register (MHCR); comparison between the two data-sets using correlation analysis, and analysis of sensitivity and specificity for binary variables *(Continued)*

Gender of infant (Boy/Girl/Sex unknown)	878	100	874	99.5	874	99.5	862	99.2	0.973 (C)
Singleton birth/multiple births	877	99.9	878	100	877	99.8	875	99.7	0.908 (C)
Mode of delivery (vaginal/instrumental vaginal/caesarean section)	876	99.8	876	99.8	874	99.5	857	98.0	0.946 (C)
If caesarean section, elective CS/emergency CS[e]	130/115	88.5	129/128	99.2	110	84.6	102	92.7	0.841 (C)

Comparison between the two data-sets using correlation analysis, and analysis of sensitivity and specificity for binary variables.
[a]Correlation analysis: C = Cohen's kappa, P = Pearson´s correlation coefficient, S = Spearman`s correlation coefficient;
[b]Measures are calculated for those who have undergone alcohol screening (n = 650). The denominator is the total no of "Yes" responses. Denominator in the Medical records =650. Denominator in the MHCR = 771.
[c]Measures are calculated for those who have undergone ultrasound.
[d]Measures are calculated for those who have undergone OGTT. The denominator is the total no of "Yes" responses. The denominator for the medical records = 100. The denominator for the MHCR = 104.
[e]Measures are calculated for those who have undergone caesarean section. The denominator is the total no of "Yes" responses. The denominator for the medical records = 130. The denominator for the MHCR = 129.

Agreement of data in medical records and in the MHCR

Identical data in both data sources ranged from 73.9% to 99.7%. For more than half of the investigated variables (17 of 27 variables), agreement of data in both data sources reached 95% or more. Five variables reached an agreement of data in both data sources of less than 90% (Table 3). Variables with the highest frequencies of identical information in the MHCR and in the medical records were mainly data related to delivery, such as "singleton birth/multiple births", "live born child", and "gender of child". For the eleven multiple births, the agreement of birth weights of second twin was identical in both data sources (100%).

Table 4 presents the comparison between the primary data collection from the medical records and the re-collection of variables from 150 reinvestigated medical records. The degree of coverage of data in the reinvestigated medical records ranged from 86.7% to 100%; frequencies of available data in medical records were similar or improved at the re-collection with one exception. The re-collection contributed to an improvement of the number of variables with 100% available data in both data sources. In addition, the number of variables with identical data increased in comparison to the first data collection. Identical data in both data sources ranged from 64.0% to 100%. Twenty-two of the 27 variables reached agreement between data sources for 95.0% or more in the reinvestigated data collection. Furthermore, the re-collection of data improved the agreement of data, resulting in only two of the 27 variables showing an agreement in both data sources to less than 90% in the reinvestigated material.

Sensitivity and specificity

Analyses of sensitivity and specificity were performed on binary variables (Table 3). The medical record was considered to represent the true value. Sensitivity varied from 0.043 (second trimester screening) to 0.999 (live born child), and specificity ranged from 0.393 (assessment of alcohol screening prior to pregnancy) to 0.999 (use of snuff at 32 gestational weeks). For nine out of the 12 binary variables, specificity was 0.900 or higher, whereas only four out of 12 binary variables had a sensitivity of 0.900 or higher.

Systematic errors

Possible systematic errors were identified for two variables: "second trimester serum screening" and "number of ANC visits". The variable "second trimester serum screening" demonstrated identical information in both data sources for 87.4%. One of the hospitals reported an unexpected large number of performed second trimester screenings in both data sources. The reported number of "second trimester serum screening" was not consistent with the clinical practice, so we discussed this issue with the midwives working in the catchment area of this hospital. These discussions revealed that that the variable "second trimester serum screening" probably had been misunderstood, resulting in incorrect reporting of data.

The variable "number of ANC visits" showed an agreement of data in both data sources for 72.3% of the cases. The information addressing this variable in the Web application was defined as the number of visits to see a midwife at an ANC (noted on the ANC registration) until estimated date of delivery as established by ultrasound (not the actual date of birth). As pregnant women may meet other health care providers during pregnancy, such visits may have been included in the figure entered in the MHCR. A misfit of ± 1 visit was seen in 19.3% of the cases. The variation of misfiting values ranged from -7 visits to + 8 visits.

Table 4 Comparison between primary collection and re-collection of data from medical records using correlation analysis, and analysis of sensitivity and specificity for binary variables

Variable	Medical records[a]		Medical records re-collection[b]		Data available in both data sources		Identical information in both data sources		Correlation[c]	Sensitivity	Specificity
	n	%	n	%	n	%	n	%			
Variables collected at first antenatal care (ANC) visit											
Date of first visit in ANC (numerical)	150	100	150	100	150	100	116	77.3	0.773 (S)		
No of previous deliveries (numerical)	150	100	150	100	150	100	149	99.3	0.988 (P)		
Maternal weight at first ANC visit (numerical)	147	98.0	148	98.7	147	99.3	146	99.3	0.995 (P)		
Maternal height (numerical)	149	99.3	149	99.3	149	100	148	99.3	1.000 (P)		
Smoking at first ANC visit (Yes/No)	149	99.3	149	99.3	149	100	148	99.3	0.794 (C)	[d]	1.000
Use of Snuff at first ANC visit (Yes/No)	150	100	150	100	150	100	146	97.3	0.793 (C)	0.667	1.000
Assessment of alcohol screening prior to pregnancy (AUDIT) (Yes/No)	130	86.7	130	86.7	130	86.7	121	93.1	0.729 (C)	0.972	0.136
If Yes, AUDIT score (numerical)[e]	113/109	96.5	108/106	98.1	102	90.3	100	98.0	0.987 (P)		
Variables collected at 4 to 16 weeks postpartum											
Prenatal diagnostics											
Amniocentesis (AC) (Yes/No)	150	100	150	100	150	100	150	100	1.000 (C)	1.000	0.983
Chorion Villus Sampling (CVS) (Yes/No)	150	100	150	100	150	100	150	100	1.000 (C)	[d]	0.992
Combined Ultrasound and Biochemical screening (CUB) (Yes/No)	147	98.0	149	99.3	147	98.6	142	96.6	0.912 (C)	0.919	0.941
Second trimester Serum Screening (Yes/No)	148	98.7	150	100	148	98.7	148	100	[f]		
Ultrasound examination at 16 – 21 gestational weeks (Yes/No)	147	98.0	147	98.0	147	98.0	145	99.0	0.246 (C)	0.975	[d]
Estimated date of delivery (ultrasound) (numerical)[g]	147	100	147	100	147	100	145	98.7	0.955 (S)		
Oral Glucose Tolerance Test (OGTT) performed (Yes/No)	149	99.3	149	99.3	148	98.0	144	98.0	0.819 (C)	1.000	0.986
If Yes, 2-hour value of plasma glucose at OGTT (numerical)[h]	13/10	77.0	10/9	90.0	9	69.2	9	100	1.000 (P)		
Smoking at 32 gestational weeks (Yes/No)	145	96.7	145	96.7	145	100	145	100	1.000 (C)	1.000	1.000
Use of Snuff at 32 gestational weeks (Yes/No)	145	96.7	145	96.7	145	100	144	99.3	0.797 (C)	1.000	1.000
Maternal weight, last data entry after 35 gestational weeks (numerical)	142	94.7	141	94.0	141	99.3	137	97.2	1.000 (P)		
No. of ANC visits until estimated date of delivery (numerical)	150	100	150	100	150	100	96	64.0	0.890 (P)		
Date of delivery (numerical)	150	100	150	100	150	100	149	99.3	0.975 (S)		
Live born child (Yes/No)	150	100	150	100	150	100	150	100	[f]	1.000	1.000

Table 4 Comparison between primary collection and re-collection of data from medical records using correlation analysis, and analysis of sensitivity and specificity for binary variables *(Continued)*

Birth weight (numerical)	150	100	150	100	150	100	140	93.3	0.997 (P)
Gender of infant (Boy/Girl/Sex unknown)	150	100	150	100	150	100	149	99.3	0.987 (C)
Singleton birth/multiple births	150	100	150	100	150	100	150	100	1.000 (C)
Mode of delivery (vaginal/instrumental vaginal/caesarean section)	150	100	150	100	150	100	149	99.3	0.983 (C)
If caesarean section, elective CS/emergency CS[i]	23/22	95.7	23/23	100	22	95.7	22	100	1.000 (C)

[a]Primary collection of data from medical records.
[b]Re-collection of data from medical records.
[c]Correlation analysis: C = Cohen's kappa, P = Pearson´s correlation coefficient, S = Spearman`s correlation coefficient.
[d]Sensitivity or specificity not possible to calculate since one or more of the cells in the calculation includes zero.
[e]Measures are calculated for those who have undergone alcohol screening. The denominator is the total no of "Yes" responses. Denominator in the Medical records (n = 113), denominator in the MHCR (n = 108).
[f]Cohen's kappa is not calculated as one of the variables is a constant.
[g]Measures are calculated for those who have undergone ultrasound.
[h]Measures are calculated for those who have undergone OGTT. The denominator is the total no of "Yes" responses. Denominator for the medical records (n = 13), denominator for the MHCR (n = 10).
[i]Measures are calculated for those who have undergone caesarean section. The denominator is the total no of "Yes" responses. Denominator for the medical records (n = 23), denominator for the MHCR (n = 23).

Discussion

This is the first time that the validity of data entered in the MHCR has been investigated. Data from 878 medical records were compared with corresponding data registered in the MHCR. The information registered in the medical records was regarded as the gold standard. Data entered in the MHCR presented a strong correlation to corresponding data in the medical records. More than half of the variables under study demonstrated identical information in both data sources to a level of 95% or more. Five of the 27 studied variables showed an agreement of less than 90% in both data sources. A second re-collection of the same variables of a subset of 150 medical records of the original sample, performed to further validate the primary data collection in this study, increased the number of variables with identical information in both data sources. Possible sources of systematic errors in the MHCR were identified for two variables.

Degree of coverage of data

The findings of this study presented a sufficient degree of coverage of data in the medical records under study. Data from the medical records have been transferred to the Swedish Medical Birth Register (MBR) since 1973. Previous studies have shown that most variables in the MBR demonstrate sufficient degree of coverage of data [12,13].

The estimated proportion of registered pregnancies in MHCR during 2010 and 2011 were 81% and 85%, respectively (personal communication). Missing MHCR data could be the result of midwives failing to enter data for all pregnant women as this work task is not compulsory and the fact that providing data is voluntarily (i.e., pregnant women can choose to opt out). However, missing data related to opting out is considered a minor issue (personal communication).

The degree of coverage of data entered in the MHCR was high for most variables in our study. The data in the MHCR were entered by the midwife working in the ANC; some information was available in the medical records and some information was provided orally by the pregnant woman. The variables regarding prenatal diagnostics in the MHCR demonstrated a relatively lower degree of coverage than other included variables, although it was still high. A possible explanation for this relatively lower degree of coverage may be the design of this question in the MHCR Web application. Only after the midwife registered "yes" for the question "Have any foetal diagnostics been performed?" is the second option displayed. In the Swedish MBR, an improvement of data quality regarding amniocentesis and chorionic villus sampling was found when the location of these variables in the medical records was changed [11]. Hence, rephrasing and redesigning these questions in the Web application may further improve the degree of coverage of data for variables related to prenatal diagnostics.

To our knowledge, no previous studies have monitored how primary data are registered in the medical records or have investigated the validity of primary data in relation to data included in the medical records. Our study shows that some variables demonstrated a higher degree of coverage in the MHCR than in the medical records. Some studies that use vital statistics databases

for perinatal epidemiology have a major limitation: the data these studies use, although considered the gold standard, have not been evaluated for their reliability and validity [14].

Agreement between data sources

The agreement of data in both data sources was high for most variables (Tables 3 and 4). To analyse correlation of categorical data, Cohen's kappa was used. Cohen's kappa is defined only for a square table and is strongly influenced by prevalence (e.g., number of "yes" responses). When there is a high level of correlation between two variables and when one of four cells is empty, the performance of Cohen's kappa declines. This decline was the case for the variable "use of snuff", where Cohen's kappa was calculated to 0.540, although data were identical for 98.9% of cases in the medical records and in the MHCR. Another example was the variable "chorionic villus sampling", where Cohen's kappa was calculated to be 0.176, although the proportion of identical data in medical records and in the MHCR reached as high as 98.9%. In these cases, the proportion of identical information in both data sources provided more valuable information than Cohen's kappa provided.

Our findings of agreement between the data sources were similar to the findings reported in a pilot study that assessed data quality in the Uniform Data Set (UDS) used by the American Association of Birth Centers [15]. In this pilot study, a care provider entered data online on four occasions; the data addressed demographic characteristics, risk factors, process of care, and maternal and infant outcomes. The agreement of variables from medical records and the UDS varies from 87.5% to 100%.

In an American evaluation of the use of electronic health records in emergency medical services, electronic data processing was compared to manual data processing. The results show good to excellent agreement between the two approaches [16]. In the Swedish setting, there is a disadvantage when data are entered in the MHCR, as data from the medical records currently cannot be automatically exported to the MHCR. All registrations in the MHCR are made manually by midwives in an ANC. Despite these potential sources of manual mistakes when registering data, the findings in our study indicate that the accuracy of data registered in the MHCR reaches a level of good to very good.

Sensitivity and Specificity

Variables characterized by one of the binary response options ("yes" and "no") demonstrated either a high specificity and a low sensitivity or a low specificity and a high sensitivity. Binary variables demonstrating a high specificity and a low sensitivity were "use of snuff", "smoking", "chorion villus sampling", and "second trimester screening". In contrast, variables characterized by a majority of "yes" responses demonstrated high sensitivity and low specificity (i.e., "assessment of alcohol screening prior to pregnancy", "ultrasound examination at 16-21 gestational weeks", and "live born child"). These results indicate that midwives performing data entry are more prone to enter results that are expected than unexpected. Similarly, an American study investigating the correctness of data in a computerized perinatal database found that there is greater likelihood to overlook a given diagnosis than to score positive a disease that does not occur [17]. A review on quality of data in perinatal health databases, including 43 validation studies, shows that most conditions and procedures demonstrate high specificities, indicating few false positives [18]. Most of the binary variables in our study demonstrated a low prevalence of the investigated outcome. This finding may explain why only four of 12 variables showed a sensitivity exceeding 0.900.

Systematic errors

This study revealed two potential systematic errors when registering data in the MHCR. First, the analysis demonstrated a misinterpretation at one of the participating hospitals regarding the registration of "second trimester serum screening" in the catchment area. An English study reveals that some midwives (7.7%) believe that they are not sufficiently prepared to inform patients about available foetal screening methods. The majority of midwives feel they are prepared to offer their patients information about screening, but when testing the level of knowledge of the conditions detectable by the available screening tests, the knowledge does not match the preparedness [19]. The situation presented in the English study might be applicable to the Swedish setting as well. The available methods for prenatal screening and prenatal diagnostics have rapidly increased over the last decade, resulting in more complex information and counselling needs [10], so some midwives working in an ANC might not have had sufficient knowledge to correctly enter data in the MHCR. The second possible systematic error found was when addressing the number of ANC visits during pregnancy. A quality study of the Swedish Medical Birth Register found that information on the number of ANC visits is missing in approximately 11% of the cases [10]. Our study found that the degree of coverage of this variable was high for both data sources, but the agreement between the data sources was not as high. A possible source for the lower accuracy could be related to insufficient instructions in the MHCR manual. Most of the incorrect values ranged ± one visit; a possible explanation for this is that visits after 40 gestational weeks or visits to the outpatient specialised clinic might have been included

in the MHCR data. Improvements in the MHCR user manual might increase the level of correct data in the MHCR.

Clinical importance

Quality register data are used for quality improvement and management within the health services as well as for research purposes. Therefore, it is of considerable importance that the improvements, decision-making, and results presented must be grounded in reliable and valid data. The benefit of the MHCR is the composition of the data, which include demographic, medical, and psychological aspects of the pregnancy, the delivery, and the postpartum period. Additionally, the data may be presented on a local, regional, and national level of the ANC, enabling comparisons of provided health care and outcomes of pregnancy and delivery. Despite manually registering data in the MHCR, the vast majority of variables included in the MHCR show very good agreement with corresponding information in the medical records. The findings in this study indicated that the data available from the MHCR are reliable enough to be used in clinical quality work and for research purposes.

Further studies

As the data are registered manually in the MHCR by midwives in an ANC, the experiences of midwives is important to address – How do midwives experience this work? Furthermore, it would be of interest to find out how data available in the MHCR are used for clinical improvements and quality aspects of health care at the local and regional levels of the ANC.

Methodological considerations

One of this study's strengths is its design. Data were extracted and analysed in two steps: a primary data extraction from 878 medical records and a secondary data extraction of the same variables for a subset of 150 medical records from the primary sample. The re-collection of data was performed by two midwives (i.e., two of this paper's authors) with extensive experience working in an ANC. This experience may have contributed to the improved quality of the data with increased statistical agreement between datasets. Data extracted by professionals other than midwives might be less accurate as these professionals may have much less experience evaluating and registering this type of data, a disadvantage that may have led to problems identifying the correct information.

Another strength of this study is the geographical variation of the included hospitals. The data extraction was performed at clinics in large cities as well as in small clinics located in more rural areas in Sweden. The selection of hospitals, in part, was determined by convenience as some of the authors were affiliated with five of these hospitals. Four other hospitals were selected with complementary characteristics in relation to the first five selected hospitals. The first author had close contact with the administrators at these hospitals in order to enhance the quality of the data collection. We believe that the selected hospitals sufficiently reflect the general characteristics of clinical settings in contemporary hospitals and ANC in Sweden.

The goal was to collect data for 900 medical records, 100 medical records from each hospital. In 2011, the degree of coverage of data was 85% in the MHCR (personal communication); that is, data were not available in the MHCR for 15% of pregnant women in Sweden for 2011. To identify 100 consecutive individuals with data in both medical records and the MHCR, we first collected the personal identity number of 120 individuals in the birth logs (from March 1), resulting in the identification of 100 women who had delivered at each hospital. Despite considerable efforts, this goal was not achieved as some administrators did not fully complete the Excel-protocols. Administrators of seven of the nine hospitals did not provide complete datasets. However, the number of missing cases (n = 22) corresponds to 2.4% of the goal, indicating that these missing cases could not have critically influenced the results of this study. Mean background characteristics on maternal age, height, weight, and BMI were 30.7 yrs, 166.2 cm, 67.9 kg, and 24.6 kg/m^2, respectively in our study. The corresponding results in the MHCR for 2011 (N = 89 313) were 30.7 yrs, 166.2 cm, 68.4 kg, and 24.7 kg/m^2, indicating that the study sample was representative for the year under study (personal communication).

Conclusions

Comparing data from medical records – the gold standard – with data registered in the MHCR, we found that most variables in the MHCR demonstrated good to very good degree of coverage of data, agreement, and internal validity. Hence, data from the MHCR may be regarded as reliable when used for evaluation, planning, and decision-making in Swedish maternal health care services as well as for research purposes.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

KP, IM, MP, and ML designed the study, organized the data collection, performed analyses of materials, and drafted the manuscript. ML contributed specifically with statistical competence. MH contributed to study design, interpretation of results, and drafting of the manuscript. CN contributed to study design, data collection, and drafting of manuscript. IH and YS contributed to data collection and drafting of the manuscript. All authors read and approved the final manuscript.

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Author details
[1]Department of Clinical Sciences, Obstetrics and Gynecology, Umeå University, Umeå, Sweden. [2]Dalarna University, School of Health and Social Studies, Falun, Sweden. [3]Umeå School of Business and Economics, Department of Statistics, Umeå University, Umeå, Sweden. [4]Department of Clinical Science and Education, Södersjukhuset, Karolinska Institutet, Stockholm, Sweden. [5]Department of Research and Development, Västernorrland County Council, Västernorrland, Sweden. [6]Primary Health Care, Parental and Child Health Care, Östersund, Sweden. [7]Primary Health Care, Maternal Health Care Unit, Örebro, Sweden.

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RESEARCH ARTICLE Open Access

User perspectives on the Swedish Maternal Health Care Register

Kerstin Petersson[1*], Margareta Persson[2], Marie Lindkvist[3], Margareta Hammarstrm[4], Ingrid Haglund[5], Carin Nilses[6], Yvonne Skogsdal[7] and Ingrid Mogren[1]

Abstract

Background: Established in 1999, the Swedish Maternal Health Care Register (MHCR) collects data on pregnancy, birth, and the postpartum period for most pregnant women in Sweden. Antenatal care (ANC) midwives manually enter data into the Web-application that is designed for MHCR. The aim of this study was to investigate midwives experiences, opinions and use of the MHCR.

Method: A national, cross-sectional, questionnaire survey, addressing all Swedish midwives working in ANC, was conducted January to March 2012. The questionnaire included demographic data, preformed statements with six response options ranging from zero to five (0 = totally disagree and 5 = totally agree), and opportunities to add information or further clarification in the form of free text comments. Parametric and non-parametric methods and logistic regression analyses were applied, and content analysis was used for free text comments.

Results: The estimated response rate was 53.1%. Most participants were positive towards the Web-application and the included variables in the MHCR. Midwives exclusively engaged in patient-related work tasks perceived the register as burdensome (70.3%) and 44.2% questioned the benefit of the register. The corresponding figures for midwives also engaged in administrative supervision were 37.8% and 18.5%, respectively. Direct electronic transfer of data from the medical records to the MHCR was emphasised as significant future improvement. In addition, the midwives suggested that new variables of interest should be included in the MHCR e.g., infertility, outcomes of previous pregnancy and birth, and complications of the index pregnancy.

Conclusions: In general, the MHCR was valued positively, although perceived as burdensome. Direct electronic transfer of data from the medical records to the MHCR is a prioritized issue to facilitate the working situation for midwives. Finally, the data suggest that the MHCR is an underused source for operational planning and quality assessment in local ANC centres.

Background

Antenatal care

Almost all pregnant women in Sweden attend antenatal care (ANC), a health service free of charge for pregnant women [1]. National and local guidelines regulate the health care provided at both public and private ANC centres. Midwives working in ANC are responsible for surveillance of pregnant women in accordance with current guidelines, and providing referral for obstetric assessment when potential complications are detected. In addition to surveillance of pregnancies, ANC midwives provide parental support, counselling on family planning, and screening for cervical cancer [1]. Furthermore, midwives manage different administrative systems related to the provided health care, such as registration of data in electronic medical records. Swedish ANC centres are mainly organized within primary health care, and the majority of the ANC centres monitor up to 200 pregnant women per year (personal communication). The mean number of pregnant women requiring health care per full time employed midwife and year is estimated to be 85, a figure that has been stable during the last decade (personal communication). The midwives work tasks at ANC centres in Sweden does not include birth assistance.

* Correspondence: kerstin.petersson@sodersjukhuset.se
Equal contributors
[1]Department of Clinical Sciences, Obstetrics and Gynecology, Ume University, Ume, Sweden
Full list of author information is available at the end of the article

Sweden is divided into 21 counties, including 43 maternal health care areas. The number of ANC centres differs in each maternal health care area depending on the area s population. For each maternal health care area, a senior consultant obstetrician and a senior consultant midwife provide local medical guidelines based on national recommendations and aspects of local health care organization [1].

Health data registers and quality registers in Sweden

The Swedish National Board of Health and Welfare (NBHW) administer a number of health data registers that monitor the general population. The first register to monitor the general population the Cause of Death Register started to collect data in 1952. In later years, the Swedish Cancer Register (1958), the Swedish Patient Register (1968), and the Swedish Medical Birth Register (1973) began collecting data. All health data registers are regulated by the Health Data Law in the Swedish Code of Statutes (1998:543), a law that requires the health care system and patients to provide these registers the requested information [2].

During the last decades, an increasing number (N = 79 at present; personal communication) of quality registers have been established in Sweden [3]. All national quality registers are monitored and approved for governmental financing by an Executive Committee in a central organization of the Swedish counties. All quality registers have been initiated by Swedish health care professional associations, in different medical areas of interest. Quality registers collect data on patient characteristics, diagnoses, medical measures and interventions, and health outcomes. Both health data registers and quality registers use the personal identification number each Swedish citizen is given, allowing for the identification of each patient if the need arises [4]. This type of identification system (health data systems containing personal information) requires secure protocols such as a secure login system where each quality register user identifies himself or herself using an individual code [2]. In contrast to the health data registers, patients are not legally compelled to provide data for quality registers, so all patients are to be informed about the quality register and have an opportunity to withhold their data from the MHCR. Quality registers are regulated by the Swedish code of statutes 2008:355 [2].

The Swedish Maternal Health Care Register

Established in 1999, the Swedish Maternal Health Care Register (MHCR) is a quality register that collects data on pregnancy, birth, and the postpartum period, including data on the individual pregnant woman and her child [3]. The MHCR aims to provide the health care system with valid data that can be used to improve Swedish health care services. During 2007 to 2009, the MHCR underwent a substantial revision of its variables, and technical solutions. A revised version of the MHCR including a new Web-application was launched on 1 January 2010 [3].

Using a Web-application, ANC midwives manually enter all data into the MHCR. Data-entry is performed on two occasions early pregnancy and after birth. The first dataset, including 14 variables, is entered when the pregnant woman registers with the ANC centre, usually during the first trimester. This dataset, as reported by the pregnant woman, includes background characteristics such as parity, maternal weight, height, smoking habits, educational level, and self-rated health. The second dataset is entered after birth and includes information on pregnancy, maternal and fetal outcomes, and the postpartum period (e.g., smoking habits during pregnancy, prenatal diagnostics, mode of birth, date of birth, birth weight, occurrence of gestational diabetes mellitus, number of antenatal visits, participation in prenatal education group, and breastfeeding at four weeks post-partum). In total, the MHCR includes 36 variables covering background data, pregnancy, birth, and postpartum outcomes. Although the objective of the MHCR is to include data on all pregnant women who attend ANC centres, the coverage of individual data on pregnant women in the MHCR during 2011 and 2012 was 81% and 85% of all pregnant women, respectively (personal communication).

Rational for the study

There is no previous study investigating the user perspectives of the MHCR; hence the rationale of this study was to investigate midwives experiences, opinions, and use of the MHCR in order to further develop the register.

Aims

The overall aim of this study was to investigate midwives experiences, opinions and use of the Swedish Maternal Health Care Register. Specific aims to explore were: *i*) how midwives experience using the MHCR Web-application for data entry; *ii)* how midwives use MHCR in their daily work; *iii)* how and to what extent MHCR data are utilized in operational planning of health services; and *iv)* user opinions about potential improvement of the MHCR.

Methods

Study design and study sample

This national cross-sectional study used a questionnaire survey addressed to all midwives currently working in Swedish ANC centres and who were eligible to conduct data entry or use data from the MHCR. In addition, all senior consultant midwives representing each MHCA were invited to participate in the study with an exception of three senior consultant midwives, as they were

authors of this study (KP, IH, and YS). The survey was performed between January and March 2012.

Questionnaire

A questionnaire was developed including in total 62 items. The questionnaire was divided into the following sections: *i*) background characteristics of participants; *ii*) design of the Web-application; *iii*) data entry of individual data; *iv*) user manual; and *v*) online reports that could be created by users from the MHCR. Section *v* was divided into two more parts; participants exclusively engaged in patient-related work task answered part one and participants who had reported administrative supervision answered part two. The latter were asked to answer additional questions on how data from MHCR were used in their daily administrative work. A majority of the items included in section *ii* through *v* were formulated as preformed statements with six Likert-type scale options (0 = totally disagree and 5 = totally agree). Most of the statements were written to reflect a positive experience (e.g., *The manual gave me the information I needed*), although two statements were written to reflect a negative experience, *(The register is burdensome* and *I question the benefit of the register*). These latter two statements, characterized by a negative expression, were formulated due to the pre-understanding of the authors related to the experiences conveyed by midwives working in ANC centres.

To complement the preformed statements, 13 spaces for free text comments were placed after each subsection in the questionnaire to provide the participants an opportunity to express whatever opinion they would like or to add further information to their answer related to the topic of the section. Before distributing the final version of the questionnaire, a pilot version was tested among purposively selected ANC midwives (N = 14) working in five different MHCA. This pilot study resulted in one minor modification of one variable in the questionnaire, (Additional file 1: The Maternal Health Care Register questionnaire).

Data collection procedures

As an initial step, the first author (KP) sent an e-mail to the senior consultant midwives in all maternal health care areas (N = 43) to ascertain the number of ANC midwives currently employed in each maternal health care area. All senior consultant midwives provided the number of ANC midwives in their maternal health care area; from these numbers, the total number of ANC midwives at the time of the data collection was estimated to be 1863.

An e-mail with information about the purpose of the questionnaire study and the procedure of distribution of the questionnaire to all midwives in each maternal health care area was sent to all senior consultant midwives (N = 43); i.e. approximately one month prior to the start of the national survey. In January 2012, the questionnaire was distributed by e-mail to all senior consultant midwives for further distribution to the midwives working in ANC centres in each maternal health care area. The attached information informed the eligible participants to print out the questionnaire on paper, respond it anonymously by returning it by post mail to the senior consultant midwife in each maternal health care area. Thereafter, each senior consultant midwife sent the collected questionnaires to the first author (KP). By answering the questionnaire, midwives, i.e. participants, were assumed to have given their consent to participate in the study. The procedure for collecting the questionnaires completed by the senior consultant midwives differed from the procedure for collecting the questionnaires completed by ANC midwives as the first author was acquainted to all senior consultant midwives. Therefore, these questionnaires were sent to a secretary to secure non-identification of the sender.

For each maternal health care area, the questionnaire was marked with a unique code representing the specific maternal health care area (No 1 43). The questionnaires specifically delivered to the senior consultant midwives were labelled with the code 44. This procedure of labelling questionnaires responding to maternal health care area enabled the authors to estimate the response rate for each maternal health care area as well as for the group of senior consultant midwives. In total, two reminders were sent by e-mail to eligible participants via the senior consultant midwives of the maternal health care area.

Study protocol

The authors developed an Excel-protocol to register the numeric variables and a Word-protocol for the free text comments. The 13 free text comments in the questionnaire corresponded to 13 sections in the Word-protocol, where all comments by the participants were noted. Each statement by a participant related to the specific section was labelled in the Word document by the number of the participant and the maternal health care area to which the participant belonged. A secretary working in the project registered all data. After completed registration of numeric data, the Excel-protocol was transformed into SPSS format for further analysis (SPSS, vs. 20).

Statistics

Before the analysis of the 49 preformed statements, the participants were categorized into three groups related to work characteristics: group A included midwives exclusively engaged in patient-related work; group B included midwives engaged in both patient-related work

tasks and administrative supervision; and group C included midwives exclusively engaged in administrative supervision. When calculating differences between the groups with or without administrative supervision work tasks, group B and C were merged, as group C consisted of only 24 participants (2.4%).

Analyses of data were done using parametric and non-parametric methods. The preformed statements were accompanied with Likert-type scale answering options (0 to 5). In the analysis, a summary of the values of 3 to 5 (i.e., values indicating a high grade of agreement) was calculated and presented. Odds ratios (OR) and their 95% confidence intervals were calculated using logistic univariate and multivariate regression analyses.

Independent variables

For the regression analysis, the independent variables were dichotomised. Age of participants was divided in two categories: 27 to 49 years and 50 to 69 years. Participants work experience as ANC midwives was divided into two categories: 0 to 10 years and 11 years or more. In addition, participants were dichotomised into groups related to work tasks (i.e., participants with patient-related work tasks exclusively and participants with work tasks including part-time or full-time administrative supervision). Participants were also categorized according to how often they entered data in the MHCR: data entry once a week or more often and data entry a few times per month or less often. Finally, the participants were categorized according to whether the midwife worked in a public or private ANC centre.

Dependent variables

Each preformed statement was used as a dependent variable in regression analysis and was dichotomized into two groups: 0 2 (indicating less agreement) and 3 5 (indicating higher agreement).

Analysis of free text comments

The analysis of the free text comments presents a range of opinions and does not provide any true quantitative estimation. All free texts were read and analysed using inductive content analysis [5]. First, all comments were read thoroughly to obtain a sense of the data. Second, all comments were coded to reflect the content of the comment. The codes were collected in coding sheets and then organised by comparing the codes. Third, categories and subcategories were established while organising the data. The categories provided information aimed at increasing understanding and generating knowledge regarding the phenomenon under study (i.e., the ANC midwives experiences as users of the MHCR). During the analysis, the findings were discussed until consensus was established. The analysis resulted in five categories with 15 subcategories.

Ethical approval

The Regional Ethical Board at Ume University (Ume, Sweden) approved the study (Dno 2012-44-31 M).

Results

Table 1 presents characteristics of MHCA and response rates. At the time of the study, we estimated the number of ANC midwives working in Sweden to be 1863 and 989 of these responded to the questionnaire, resulting in an overall response rate of 53.1%. The response rates varied between the different counties, ranging from 21.5% to 77.6%. Stockholm County the largest county in Sweden and with five MHCA accounting for 25.6% of all births in Sweden had a response rate of 46.2%. The response rate for the group of senior consultant midwives was 92.5% (37/40).

Background characteristics of the participants are presented in Table 2 and the age-distribution of participants is presented in Figure 1. The percentage of midwives with patient-related work exclusively (group A) was 89.1%. The percentage of midwives with patient-related work and part-time administrative supervision (group B) was 8.5%. The percentage of midwives with administrative supervision exclusively (group C) was 2.4%. One participant did not report a category. The mean age of all participants was 51.1 years, ranging from 27 to 69 years. The mean age was highest (53.7 years) in group C. The mean age of all midwives in category B and C (53.6 years) was significantly higher than midwives included in category A (50.8 years, $p = 0.002$). For all participants, the mean number of years of work as a midwife was 21.4 years, whereas the corresponding figure for midwives included in categories B and C were significantly higher (24.8 years, $p = 0.001$). For all participants, the mean number of years as an ANC midwife was 13.3 years, a finding that suggested that during their career as a midwife the participants had performed other work tasks apart from working in an ANC centre (mean time of 8.1 years). A minor part of the midwives (6.0%) worked less than 0.50 of a full time equivalent while the majority (69.9%) reported a level of employment of 0.75 of a full time equivalent or more. Most midwives (80.4%) entered data in the MHCR at least once a week; this percentage included midwives who entered data daily (7.7%).

Table 3 presents the results of the preformed statements divided into three main sections: 1) all midwives; 2) midwives executing patient-related work only (Group A); and 3) midwives executing patient-related work tasks and administrative supervision and midwives executing administrative supervision exclusively (Group B and Group C). The response rates for preformed statements

Table 1 Number of Maternal Health Care Areas (MHCA) and births per county, estimated number of midwives in each county, and response rate per county

County[a]	No. of MHCA	No. of births n (%)[b]	No. of midwives n (%)[c]	Response rate n (%)[d]
Stockholm	5	28 932 (25.6)	413 (22.1)	191 (46.2)
Vstra Gtaland	6	19 279 (17.0)	312 (16.7)	174 (55.8)
Skne	5	15 672 (13.8)	205 (11.0)	76 (37.1)
stergtland	3	5 085 (4.5)	73 (3.9)	31 (42.5)
Uppsala	1	4 124 (3.6)	70 (3.8)	42 (60.0)
Jnkping	3	3 911 (3.4)	66 (3.5)	46 (69.7)
Halland	2	3 236 (2.8)	63 (3.4)	39 (61.9)
rebro	1	3 208 (2.8)	65 (3.5)	44 (67.7)
Srmland	1	3 010 (2.6)	65 (3.5)	14 (21.5)
Gvleborg	1	2 874 (2.5)	50 (2.7)	32 (64.0)
Vstmanland	1	2 852 (2.5)	50 (2.7)	25 (50.0)
Vsterbotten	2	2 835 (2.5)	49 (2.6)	38 (77.6)
Dalarna	1	2 819 (2.5)	65 (3.5)	34 (52.3)
Vrmland	1	2 793 (2.5)	63 (3.4)	38 (60.3)
Kalmar	2	2 396 (2.1)	54 (2.9)	32 (59.3)
Vsternorrland	2	2 382 (2.1)	35 (1.9)	24 (68.6)
Norrbotten	1	2 321 (2.1)	61 (3.3)	17 (27.9)
Kronoberg	2	2 089 (1.8)	36 (1.9)	21 (58.3)
Blekinge	1	1 522 (1.3)	25 (1.3)	17 (68.0)
Jmtland	1	1 271 (1.1)	35 (1.9)	12 (34.3)
Gotland	1	566 (0.5)	8 (0.4)	5 (62.5)
Total	43	113 177 (100)	1863 (100)	989 (100)
SCM[e]			43	37/40[f] (92.5)

[a]All counties in Sweden are presented (N = 21).
[b]Number of births 2012. Data from Population in the country, counties and municipalities on 31/12/2012 and Population Change in 2012 [Internet] Statistics Sweden; 2012 (cited2014, February 4) http://www.scb.se/en_/Finding-statistics/Statistics-by-subject-area/Population/Population-composition/Population-statistics/Aktuell-Pong/25795/Yearly-statistics Municipalities-Counties-and-the-whole-country/Population-in-the-country-counties-and-municipalities-on-31122012-and-Population-Change-in-2012/.
[c]Presented as proportion of all midwives in antenatal care (n = 1863) (personal communication).
[d]Presented as proportion of number of midwives in each county.
[e]Senior Consultant Midwives.
[f]Three Senior Consultant Midwives were excluded from participating in the study since they were authors of this article and did not respond the questionnaire. Thus, the denominator in this calculation is 40.

included in the three different sections varied as follows: section 1 85.0% to 97.7%; section 2 85.2% to 95.8%; and section 3 73.1% to 91.7%.

Response to preformed statements all participants

These results are presented in Table 3 (section 1). Overall, the participants expressed relatively high agreement (i.e., summary value of 3 to 5) for most statements. For example, the statement *It is easy to get an overview* was graded between 3 and 5 by 90.1%, and the corresponding figure for the statement *The text is easy to understand* was 95.7%. The statement *The start page has an appealing layout* presented a lower level of high agreement (74.7%). Of all the participants, 51.5% reported that they had read the manual; accordingly, 48.5% had not read the manual. Of those participants who had read the manual, 96.1% (a value between 3 and 5) agreed with the statement *The text is easy to understand* and 92.5% (a value between 3 and 5) agreed with the statement *The manual provided me with the information I needed* . There were four statements regarding first and second data entry. For the first data entry, the statement *The questions are easy to understand* were graded between 3 and 5 by 98.2%. The corresponding figure for the same statement for second data entry was 98.0%.

Statements participants in group A

These results are presented in Table 3 (section 2): 70.7% of the midwives executing exclusively patient-related

Table 2 Characteristics of participating midwives (N = 989) and test of difference between two groups using *t*-test for numeric variables and Chi-squared test for categorical variables

Variable	All participating midwives	Group A[a]	Group B[b]	Group C[c]	P-value[d]
		n = 880 (89.1%)	n = 84 (8.5%)	n = 24 (2.4%)	
Age (yrs) (n, %)	983 (99.4)	874 (88.0)	84 (8.5)	24 (2.4)	
Mean (SD)	51.1 (8.7)	50.8 (8.9)	53.6 (6.6)	53.7 (6.3)	0.005[e]
Median	53.0	52.5	55.0	55.0	
Range	27-69	27-69	39-64	42-64	
Work experience as midwife in yrs (n, %)	941 (95.1)	833 (88.5)	83 (8.8)	24 (2.6)	
Mean (SD)	21.4 (10.5)	21.0 (10.5)	24.7 (9.8)	25.2 (8.8)	0.001[f]
Range	0-44	0-44	4-42	9-40	
Work experience as midwife in ANC in yrs (n, %)	906 (99.3)	805 (88.9)	78 (8.6)	22 (2.4)	
Mean (SD)	13.3 (9.3)	13.0 (9.3)	16.0 (8.9)	17.9 (9.0)	<0.001[e]
Range	0-40	0-40	1-36	3-36	
Working as a midwife in public/private care (n, %)	977 (98.8)	875 (89.6)	84 (8.6)	17 (1.7)	
Public health care	836 (85.6)	757 (86.5)	63 (75.0)	15 (88.2)	
Private health care	141 (14.3)	118 (13.5)	21 (25.0)	2 (11.8)	
Level of employment (n,%)	982 (99.3)	878 (89.4)	84 (8.6)	19 (2.2)	<0.001[g]
<50%[h]	59 (6.0)	37 (4.2)	15 (17.9)	7 (36.8)	
50-75%[i]	237 (24.1)	225 (25.6)	10 (11.9)	1 (5.3)	
>75%[j]	686 (69.9)	616 (70.2)	59 (70.2)	11 (57.9)	
Registration of data in register (n, %)	975 (98.6)	873 (89.5)	84 (8.6)	17 (1.7)	<0.001[g]
Daily	75 (7.7)	68 (7.8)	7 (8.3)	0	
Several times a week	585 (59.2)	536 (61.4)	48 (57.1)	0	
Once a week	124 (12.7)	117 (13.4)	6 (7.1)	1 (5.9)	
A few times every month	155 (15.9)	134 (15.3)	19 (22.6)	2 (11.8)	
Less frequent	36 (3.7)	18 (2.1)	4 (4.8)	14 (82.4)	

[a]Group A = Midwives exclusively engaged in patient-related work tasks.
[b]Group B = Midwives engaged in both patient-related work tasks and administrative supervision.
[c]Group C = Midwives exclusively engaged in administrative supervision.
[d]Test of difference between two groups: Midwives with patient-related work tasks exclusively in one group (A) and midwives with patient-related work tasks and supervision and midwives with supervision exclusively in the other group (B, C).
[e]Mann Whitney.
[f]*t*-test.
[g]Chi-squared test.
[h]<0.50 of a full time equivalent.
[i]0.50-0.75 of a full time equivalent.
[j]>0.75 of a full time equivalent.

work agreed (a value between 3 and 5) with the statement that *The register is burdensome* ; 9.5% agreed (a value between 3 and 5) with the statement *I regularly access data on pregnant women who visit my clinic* ; and 44.7% agreed (a value between 3 and 5) with the statement *I question the benefit of the register* .

Statements participants in merged group B and C

These results are presented in Table 3 (section 3). Of midwives engaged in administrative supervision to some extent or exclusively, 18.5% had a high agreement (a value between 3 and 5) with the statement *I question the benefit of the register* . A majority (55.6%) marked a value between 3 and 5 for the statement *I regularly access data on pregnant women who visit my clinic* and 66.0% agreed (a value between 3 and 5) to the statement *The register is helpful in my administrative work* . Only 8.3% marked a value between 3 and 5 for the statement *I provide register data for development of health care* . The corresponding figure for the statement *I base financial decisions on data from the register* was 30.4%.

There were statistically significant differences for participants included in group A in relation to participants included in group B and C for the statements *The register is helpful in my clinical work* ($p < 0.001$; COR = 5.22 CI95% 3.26-8.35) and *I regularly access data on*

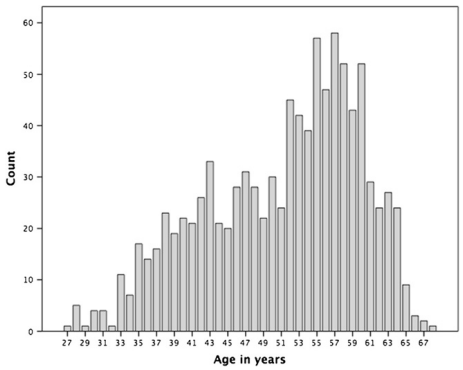

Figure 1 Participant age distribution.

pregnant women who visit my clinic ($p < 0.001$; COR = 11.79 CI95% 7.43-18.69) (Table 4). Group B and C reported more positive values (i.e., agreed with the statement to a higher extent). There were also statistically significant differences for participants included in group A in relation to participants included in group B and C for the statement *I question the benefit of the register* ($p < 0.001$; COR = 0.29 CI95% 0.16-0.49) (Table 4). A statistical difference was identified for participants in the two age groups ($p = 0.007$) and for participants in the two groups of work experience as midwives ($p = 0.004$) for the statement *The register is helpful in my clinical work* .

When adjusting for age and work years as an ANC midwife, the adjusted odds ratio remained highly increased for the statements *The register is helpful in my clinical work* (AOR = 4.46 CI95% 2.72-7.29) and *I regularly access data on women who visit my clinic* (AOR = 11.07 CI95% 6.83-17.91) (Table 4). Midwives employed in private ANC centres agreed with the statement *I question the benefit of the register* in a higher degree in relation to midwives employed in public ANC centres (Table 4). The increased odds ratio remained significant after adjustment for work characteristics (Table 4).

The OR for reporting extraction of data from online reports on pregnant women from the MHCR was much higher (OR = 11.90; CI95% 7.52-18.83) for participants engaged in both patient-related work tasks and administrative supervision (group B and C) compared to midwives exclusively engaged in patient-related work tasks.

Free text comments

The analysis of the free text comments revealed five categories and their corresponding 15 sub-categories. An overview of the categories and sub-categories are presented in Table 5. A summary of each category, including the content of its sub-categories, is presented below in a condensed form and is illustrated with quotations when applicable.

Duplicating registrations

Data entry was reported as time consuming. The midwives saw the time spent registering data as time that could have been used to encounters with pregnant women in the ANC centres. Furthermore, a sub-set of the same data was registered in the medical record as well as in the MHCR. Hence, the midwives considered these data registrations as redundant. To counter this duplication, the many midwives noted that direct data transfer from medical records to the MHCR would simplify this assignment, giving them more time to actually meet with patients. Participants also stated that they did not find it necessary for a midwife to do this work; they noted that a secretary or other administrational staff could enter data into the MHCR.

> *I understand the usefulness of the register but because of too many work tasks, it s always the register that comes second. When time is limited, you always have to prioritize health care.* (Participant no 585)

Navigating the Web-application

Participants considered the layout of the Web-application as somewhat old-fashioned and boring. Midwives expressed both positive and negative experiences navigating the software.

> *[The register] is easy to use. A bit boring layout to watch . . . but what does it matter . . . [The register is] not a major stress issue.* (Participant no 347.)

Participants expressed difficulties using the software when entering data. For example, some found it difficult to manage the data entry of a pregnant woman who had moved from one ANC centre to another between the two data entry occasions. That is, a new midwife was responsible for the health care of the woman and subsequently for the second data entry. Extensive use of the computer mouse at managing the Web-application was reported as a difficulty. Furthermore, pregnant women lacking a Swedish personal number made it difficult to enter data into the system. Participants were also concerned about revealing confidential information to other patients due to the layout of the Web-application as a list of pregnant women managed by the specific midwife was clearly visible on the start page. That is, a pregnant woman could see the names and personal numbers of other pregnant women. This situation was seen as potential compromise of patient privacy.

Understanding the variables

Some variables in the MHCR (e.g., educational level, country of origin, and occupation) were perceived as having

Table 3 Response rate and level of agreement on formulated statements related to the Maternal Health Care Register

	Response rate[a]	Values[b]						
		Totally disagree				Totally agree		Summary of
	n (%)	0	1	2	3	4	5	value 3 to 5
1. Statements responded by all participating midwives (N = 989)								
It is easy to get an overview	947 (95.8)	9 (0.9)	21 (2.2)	64 (6.8)	261 (27.6)	359 (37.9)	233 (24.6)	853 (90.1)
It is easy to orient myself	948 (95.9)	8 (0.8)	17 (1.8)	60 (6.3)	248 (26.2)	390 (41.1)	225 (23.7)	863 (91.0)
The start page has an appealing layout	866 (87.6)	33 (3.8)	52 (6.0)	134 (15.5)	345 (39.8)	196 (22.6)	106 (12.2)	646 (74.7)
The colours are appealing	844 (85.0)	9 (1.1)	35 (4.1)	99 (11.7)	295 (35.0)	273 (32.3)	133 (15.8)	700 (83.0)
The font is easy to read	943 (95.0)	3 (0.3)	8 (0.8)	33 (3.5)	188 (19.9)	397 (42.1)	314 (33.3)	898 (93.5)
The text is easy to understand	948 (95.9)	3 (0.3)	8 (0.8)	30 (3.2)	184 (19.4)	428 (45.1)	295 (31.1)	907 (95.7)
The font size works well	947 (95.8)	2 (0.2)	2 (0.2)	24 (2.5)	144 (15.2)	402 (42.4)	373 (39.4)	919 (97.0)
I get the information I need about the register	861 (87.1)	19 (2.2)	22 (2.5)	68 (7.9)	236 (27.4)	328 (38.1)	188 (21.8)	752 (87.3)
The Web- application functions well for registration	943 (95.3)	10 (1.1)	14 (1.5)	44 (4.7)	187 (19.8)	420 (44.5)	268 (28.4)	875 (92.8)
Register manual								
I have read the manual (proportion of yes answer)	493 (51.5)							
The text is easy to understand	462 (93.7)	2 (0.4)	2 (0.4)	14 (3.0)	126 (27.3)	236 (51.2)	82 (17.7)	444 (96.1)
The manual gave me the information I needed	459 (93.1)	3 (0.7)	2 (0.4)	17 (3.7)	121 (26.4)	219 (47.7)	97 (21.1)	437 (92.5)
Registration of data at first data entry								
The questions are easy to understand	966 (97.7)	3 (0.3)	2 (0.2)	12 (1.2)	83 (8.6)	379 (39.2)	487 (50.4)	949 (98.2)
The questions come in a logical order	918 (92.8)	4 (0.4)	4 (0.4)	19 (2.1)	117 (12.7)	388 (42.3)	386 (42.0)	891 (97.1)
Registration of data at second data entry								
The questions are easy to understand	953 (96.4)	1 (0.1)	2 (0.2)	16 (1.7)	128 (13.4)	425 (44.6)	381 (40.0)	934 (98.0)
The questions come in a logical order	916 (92.6)	2 (0.2)	7 (0.8)	22 (2.4)	132 (14.4)	412 (45.0)	341 (37.2)	885 (96.6)
2. Statements responded by midwives in group A[c] (n = 880)[d]								
I regularly access data on pregnant women who visit my clinic	842 (95.7)	481 (57.1)	182 (21.6)	99 (11.8)	55 (6.5)	11 (1.3)	14 (1.7)	80 (9.5)
The register is helpful in my clinical work	750 (85.2)	289 (38.5)	163 (21.7)	118 (15.7)	127 (16.9)	32 (3.6)	21 (2.8)	180 (24.0)
The register is burdensome	843 (95.8)	64 (7.6)	78 (9.3)	105 (12.5)	215 (25.4)	186 (21.9)	197 (23.4)	596 (70.7)
I gain a more coherent picture of the pregnant woman by registering data in the register	809 (91.9)	285 (35.2)	198 (24.5)	131 (16.2)	147 (18.2)	36 (4.4)	12 (1.5)	195 (24.1)
I question the benefit of the register	789 (89.7)	201 (25.5)	148 (18.8)	87 (11.0)	158 (20.0)	83 (10.5)	112 (14.2)	353 (44.7)
3. Statements responded by midwives in group B[e] (n = 84) and C[f] (n = 24). In total n = 108[d]								
I regularly access data on pregnant women who visit my clinic	99 (91.7)	20 (20.2)	11 (11.1)	13 (13.1)	22 (22.2)	17 (17.2)	16 (16.2)	55 (55.6)
The register is helpful in my clinical work	85 (78.7)	15 (17.6)	6 (7.1)	11 (12.9)	24 (28.2)	15 (17.6)	14 (16.5)	53 (62.4)

Table 3 Response rate and level of agreement on formulated statements related to the Maternal Health Care Register *(Continued)*

The register is burdensome	98 (90.7)	19 (19.4)	24 (24.5)	18 (18.4)	19 (19.4)	12 (12.2)	6 (6.1)	37 (37.8)
The register is helpful in my administrative work	94 (87.0)	17 (18.1)	7 (7.4)	8 (8.5)	15 (16.0)	28 (29.8)	19 (20.2)	62 (66.0)
I gain a more coherent picture of the pregnant woman by registering data in the register	80 (74.1)	21 (26.3)	8 (10.0)	13 (16.3)	18 (22.5)	14 (17.5)	6 (7.5)	38 (47.5)
I use register data in our operational planning	91 (84.3)	27 (29.7)	11 (12.1)	7 (7.7)	13 (14.3)	22 (24.2)	11 (12.1)	46 (50.5)
I base financial decisions on data from the register	79 (73.1)	37 (46.8)	8 (10.1)	10 (12.7)	14 (17.7)	8 (10.1)	2 (2.5)	24 (30.4)
I use register data to describe the burden of care for my clinic	95 (88.0)	24 (25.3)	7 (7.4)	12 (12.6)	13 (13.7)	23 (24.2)	16 (16.8)	52 (54.7)
I use register data to compare my clinic with other levels of health care (regions, counties, Sweden)	96 (88.9)	22 (22.9)	12 (12.5)	12 (12.5)	8 (8.3)	24 (25.0)	18 (18.8)	50 (52.1)
I present register data to my colleagues at the clinic	96 (88.9)	25 (26.0)	10 (10.4)	7 (7.3)	14 (14.6)	20 (20.8)	20 (20.8)	54 (56.3)
I perceive my colleagues as interested in clinic data	90 (83.3)	15 (16.7)	3 (3.3)	12 (13.3)	21 (23.3)	24 (26.7)	15 (16.7)	60 (66.7)
I provide register data to my supervisors	95 (88.0)	32 (33.7)	11 (11.6)	8 (8.4)	9 (9.3)	19 (20.0)	16 (16.8)	44 (46.3)
I provide register data for development of health care	84 (77.8)	57 (67.9)	13 (15.5)	7 (8.3)	5 (6.0)	1 (1.2)	1 (1.2)	7 (8.3)
I question the benefit of the register	92 (85.2)	52 (56.5)	19 (20.7)	4 (4.3)	4 (4.3)	3 (3.3)	10 (10.9)	17 (18.5)

[a]Response rate is the number of responding participants divided by 989.
[b]Values on a scale from 0 to 5 where 0 = totally disagree and 5 = totally agree.
[c]Group A included midwives exclusively engaged in patient-related work tasks.
[d]One participant did not fill in type of work executed.
[e]Group B included midwives engaged in both patient-related work tasks and administrative supervision.
[f]Group C included midwives exclusively engaged in administrative supervision.

Table 4 Univariate and multivariate regression analysis for high agreement of specified statements in relation to background characteristics

Variable	Statements*							
	The register is helpful in my clinical work				*I regularly access data on women who visit my clinic*			
	Crude OR	**CI 95%**	**Adjusted OR**	**Adjusted CI 95%**	**Crude OR**	**CI 95%**	**Adjusted OR**	**Adjusted CI 95%**
Work characteristics								
Midwives in group A	1				1			
Midwives in group B and C	5.22	3.26-8.35	4.46[a]	2.72-7.29	11.79	7.43-18.69	11.07[b]	6.83-17.91
Age (years)								
27-49	1				1			
50-69	1.55	1.12-2.38	1.15[c]	0.77-1.72	2.02	1.33-3.06	1.30[d]	0.76-2.23
Organisation								
Public ANC	1				1			
Private ANC	0.71	0.44-1.13			1.35	0.81-2.22		
Work years in ANC								
0-10	1				1			
≥11	1.60	1.16-2.19	1.36[e]	0.93-1.99	1.93	1.31-2.83	1.41[f]	0.86-2.29
Frequency of data entry								
Once a week or more often	1				1			
A few times every month or less often	0.70	0.46-1.06			1.07	0.67-1.70		
	The register is burdensome				*I question the benefit of the register*			
	Crude OR	**CI 95%**	**Adjusted OR**	**Adjusted CI 95%**	**Crude OR**	**CI 95%**	**Adjusted OR**	**Adjusted CI 95%**
Work characteristics								
Midwives in group A	1				1			
Midwives in group B and C	0.26	0.16-0.40			0.29	0.16-0.49	0.29[g]	0.16-0.51
Age (years)								
27-49	1				1			
50-69	0.81	0.61-1.07			0.973	0.73-1.28		
Organisation								
Public ANC	1				1			
Private ANC	1.00	0.67-1.47			1.70	1.15-2.48	1.79[h]	1.21-2.65
Work years in ANC								
0-10	1				1			
≥11	0.80	0.60-1.06			0.90	0.67-1.19		
Frequency of data entry								
Once a week or more often	1				1			
A few times every month or less often	0.93	0.65-1.31			1.28	0.91-1.79		

*Statements were dependent variables in calculation, see Methods section.
[a]Crude OR adjusted for age and work years in ANC.
[b]Crude OR adjusted for age and work years.
[c]Crude OR adjusted for work years and work characteristics.
[d]Crude OR adjusted for work characteristics and work years in ANC.
[e]Crude OR adjusted for age and work characteristics.
[f]OR adjusted for age and work characteristics.
[g]Crude OR adjusted for organisation.
[h]Crude OR adjusted for work characteristics.

Table 5 Overview of categories and sub-categories for free text answers

Categories	Sub-categories
Duplicating registration	Time consuming registration
	Data available in other sources
	Work task for someone else
Navigating the web-application	Old fashioned layout
	Difficulties operating the system
	Patients identity exposed
Understanding the variables	Interpretation of variables
	Redundant variables
	Lack of relevant variables
Needing education on the system	Lack of introduction to the system
	Insufficient user instructions
	Need of continuous information
Use of data in daily work	Questioning the usefulness
	Mapping the situation
	Under-utilized source

insufficient number of response alternatives. The variable self-reported health was reported as sometimes difficult for both the midwife to understand and for the pregnant women to answer. It was suggested that self-reported health should be divided into two questions: one regarding physical health and one regarding psychological health. In addition, some midwives felt that variables related to education, country of birth, self-reported health, and prenatal diagnostics were unnecessary. However, there were a number of suggestions on new variables to be included in the MHCR, (e.g., infertility, in vitro fertilization, inter-current diseases during pregnancy, medical complications during pregnancy and birth, and physical activity during pregnancy).

Needing education on the system

Participants reported that there had been an insufficient introduction to the Web-application when it was implemented in 2010. Not being properly introduced to the system aggravated the performance of the data-entry. Other comments related to insufficient instructions in the manual concerning specific situations. Participants also requested continuous update on news in the MHCR.

> *It would have been helpful if we had received instructions [when the register started] and after a time of practise had had a follow-up meeting with an opportunity to ask questions.* (Participant no 45)
> *I want more information and education on how to use the register.* (Participant no 217)

Use of data in daily work

The usefulness of data was questioned, and further, the question on insufficient validity of data was raised. A notion was that the variables included in MHCR did not reflect the content of ANC. Some participants also questioned the existence of the MHCR.

> *[I have] often wondered who is using the information [the register] and for what? Level of education is not always important, or to whom is it important?* (Participant no 575)

However, others reported using the data to understand the current situation within their own ANC centre. Additionally, data were used to compare local their ANC centre with regional and national trends. Some participants believed that data included in MHCR were underused, and results for a specific ANC data should be more regularly discussed among colleagues. It was also expressed that the data could be used in operational planning and quality assessment to a further extent.

> *Even if I don t fully use the possibilities the register offers today; that is a possibility and a development for the future.* (Participant no 836)
> *I wish that we would use the MHCR to get an overview of our pregnant women at our ANC and in comparison with other parts of the country. It has to do with burden of care! When I worked in another MHCA, we used to discuss it [the local results] together with the senior consultant midwife. Here, it is never mentioned. It is a topic only discussed in relation to the economy: if we have made mistakes concerning data entry, resulting in a lower bonus.* (Participant no 40)

Discussion

The main findings of this study demonstrate that participants in general were positive towards using the MHCR Web-application and reported the variables in MHCR as useful and appropriate. However, the majority of midwives who were exclusively engaged in patient-related work reported data entry into the register as burdensome, and four of ten midwives questioned the benefit of the register. The corresponding figures for midwives engaged in administrative supervision were substantially lower. Direct electronic transfer of data from medical records to the MHCR, was emphasized as a significant future improvement of the MHCR.

The estimated overall response rate (53.1%) was calculated from the number of participants and the estimated number of midwives working in an ANC centre at the time of the study. The midwives reported a mean total work experience of 21.4 years and they had worked in

ANC for a mean time of 13.3 years. A majority of the participants (80.4%) reported that they performed data entry in the MHCR once a week or more often. These outcomes showed that the midwives were experienced regarding both ANC and management of the MHCR.

The response rates of the preformed statements were high overall. The responses to the statements regarding orientation and layout of the Web-application and data entry demonstrated high values [3-5] (i.e., positive agreement for all participants). Approximately every second participant reported having read the manual, which might seem a surprisingly low figure.

There were no differences between participants for their evaluation of the register for the statements *I regularly access data on pregnant women who visit my clinic* , *The register is burdensome* , and *I question the benefit of the register* in relation to background characteristics such as age, work experience as midwives, or frequency of data entry in the MHCR. For these three statements, however, there was a statistical difference between midwives exclusively engaged in patient-related work (group A) and midwives engaged in administrative supervision part-time or full-time (group B and C). There was also a statistical difference between midwives employed in private and public ANC centres for the statement *I question the benefit of the register* .

The statements *I use register data in operational planning* and *I use register data to compare my clinic with other levels of health care (regions, counties, Sweden)* demonstrated the values 3 to 5 for 50.5% and 52.1% of participants, respectively (Table 3). These figures seem relatively low considering that one purpose of the quality register is to be used for quality assessment and operational planning. We therefore conclude that the MHCR currently is an under-utilized source for further development of ANC.

Very few studies investigating user experiences of quality registers have been performed. However, one study reports that Nordic departments of gynaecology are interested in participating in quality assessment register as long as participation does not mean any extra work or costs [6], findings consistent with our study. Furthermore, our participants emphasised that electronic direct transfer of data from medical records to the MHCR would substantially reduce their workload. An Australian study shows that e-health platforms result in improvement to error rates and completion levels [7]. It is plausible that a similar improvement would be seen in the MHCR if implementing electronic direct transfer of data. In a questionnaire survey from 2005 investigating the views of orthopaedic consultants in the then newly launched National Joint Registry, a concern was raised that league tables created from register data would be unreliable for both individual surgeons and for hospitals [8].

Methodological considerations

One strength of this study is that it addressed all midwives currently working in ANC centres in Sweden, so almost all users of the MHCR were given a chance to express their opinions about the register. Additionally, the participants represented all counties in Sweden. With the help of the senior consultant midwives, two reminder e-mails were sent to all participants. A previous postal questionnaire study investigating the effectiveness of follow-up procedures showed that it is worth sending at least three reminders. However, a third reminder resulted in an increased response rate of only 4.4% [9]. This low number may indicate that any further reminder would not have increased the response rate significantly in our study. The response rates for different statements were high overall. Most preformed statements were answered by more than 85% of the participants.

All authors except one had an engagement in the MHCR combined with work experience from ANC. Additionally, as most of the authors had contributed to writing medical guidelines for the ANC centres, they had experienced many encounters with ANC midwives working throughout Sweden where the experiences of using the MHCR had been discussed. The understanding from these encounters constituted the ground for the statements composed in this study. Thus, the authors of this study had significant experience in the field under study and the pilot version of the questionnaire resulted in only a minor revision. The extensive experience may be regarded as a strength as well as a weakness. Although the familiarity with the topic aided in the construction of the questionnaire, this same familiarity and the authors pre-understandings might also have excluded important questions. To address this issue, there was an opportunity of all participants to leave comments on issues that were not addressed by the preformed statements or raised in other questions.

Our study may have some other limitations. The estimated response rate was 53.1%, a relatively low percentage considering the desire to produce representative data. However, the exact number of midwives present in their work place during the data collection period may have differed from the numbers provided by the senior consultant midwives. Some eligible participants may have been on sick leave, holiday, or attending training during the study period. Hence, the actual response rate may be somewhat higher than the calculated rate. The response rates in the counties ranged from 21.5% to 77.6%. The coverage of data in MHCR (2011) for those two counties was 53% and 92%, respectively (personal communication). A Cochrane Review identifying effective strategies to increase response rates to postal and electronic questionnaires shows that a more interesting topic for eligible participants significantly increased the response rate in both postal and electronic questionnaires [10]. The response rate in our study

may thus indicate the level of engagement with the MHCR and may be a contributing factor to the proneness to respond to the questionnaire. Unfortunately, no official data are available on the number of midwives working in ANC centres or hospitals in Sweden, so the degree of non-participation can only be roughly estimated. Official data from the National Board of Health and Welfare show that the mean age and median age were 49 years [11] and 51 years, respectively (personal communication), for all working midwives (N = 7001) in Swedish health care in November 2011. In our study, the mean age of participants was 51.1 years. Since the mean age of the participants in the present study was fairly close to the official data, we believe most probably that our participants are representative for the group under study. Concerning the free comments provided by the participants, it was not possible to establish whether the midwives conveyed their total range of opinions or just a sub-set of their opinions.

Implications of this study

The results of this study show several potential improvements for the MHCR in relation to the perspectives of its users. The authors concluded, based on the free comments, that there was a call for education on how to handle the data-entry and how to access local and national data practically from the MHCR. There was also identified a need to provide information on how to use register data in quality assessment and in operational planning. After performing this study, the board of the MHCR have arranged a number of educational meetings during 2012 to 2013 in ANC throughout Sweden, inviting midwives currently working in ANC. Direct electronic transfer of data from medical records to the MHCR should become a prioritized issue to facilitate the working situation of the midwives. When electronic direct transfer of data from medical records to the MHCR will be implemented, several of the new variables suggested by the participants will be included in the MHCR.

Conclusions

MHCR was generally valued positively, although perceived as burdensome, mainly by midwives working with patient-related work exclusively. Direct electronic transfer of data from medical records to the MHCR is a prioritized issue to facilitate the work situation for midwives. The MHCR is an under-utilized source for operational planning and quality assessment in local ANC.

Additional files

Additional file 1: The Maternal Health Care Register questionnaire (MHCA code no 1-44).

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

KP, IM, MP, CN, IH, and YS designed the study. KP, IM, MP, CN, IH, and YS created the questionnaire. KP, IM, MP, and IH organized the data collection. KP, IM, MP, and ML performed the analysis. KP drafted the manuscript together with IM and MP. All authors contributed to the interpretation of the results. All authors read and approved the final version of the manuscript.

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Author details

[1]Department of Clinical Sciences, Obstetrics and Gynecology, Ume University, Ume, Sweden. [2]Dalarna University, School of Health and Social Studies, Falun, Sweden. [3]Ume School of Business and Economics, Department of Statistics, Ume University, Ume, Sweden. [4]Department of Clinical Science and Education, Sdersjukhuset, Karolinska Institutet, Stockholm, Sweden. [5]Primary Health Care, Parental and Child Health Care, stersund, Sweden. [6]Department of Research and Development, Vsternorrland County Council, Sundsvall, Sweden. [7]Primary Health Care, Maternal Health Care Unit, rebro, Sweden.

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III

Prenatal diagnosis in Sweden 2011 to 2013 – a register-based study

Kerstin Petersson[1§], Marie Lindkvist[2], Margareta Persson[3], Peter Conner[4], Annika Åhman[1], Ingrid Mogren[1*]

ABSTRACT

Background

Prenatal diagnosis involves methods used in early pregnancy as either screening tests or diagnostic methods. The aims of the study were to *i)* investigate guidelines on prenatal diagnosis in the counties of Sweden, *ii)* investigate uptake of prenatal diagnosis, and *iii)* background characteristics and pregnancy outcomes in relation to different prenatal diagnostic methods.

Methods

A retrospective cross-sectional study using data from the Swedish Pregnancy Register 2011 to 2013 (284,789 pregnancies) was performed. Additionally, guidelines on prenatal diagnosis were collected. Biostatistical and epidemiological analyses were performed including calculation of odds ratios (OR) and their 95% confidence intervals in univariate and multivariate logistic regression analyses.

[1] Department of Clinical Sciences, Obstetrics and Gynecology, Umeå University, 901 87 Umeå, Sweden

[2] Department of Statistics Umeå School of Business and Economics; Department of Public Health and Clinical Medicine, Epidemiology and Global Health; Umeå University, 901 87 Umeå, Sweden

[3] Department of Nursing, Umeå University, Umeå, Sweden

[4] Department of Obstetrics and Gynecology, Center for Fetal Medicine, Karolinska University Hospital, Stockholm, Sweden

* These authors contributed equally to this work

§ Corresponding author

Results

The national uptake of routine ultrasound examination, Combined Ultrasound and Biochemical test (CUB), Amniocentesis (AC) and Chorionic Villus Sampling (CVS) were 97.6%, 33.0%, 2.6% and 1.1%, respectively. From 2012, 6/21 counties offered CUB test to all pregnant women, nine counties at specific indications, and five counties did not offer CUB at all. One county did not have any written guidelines. Advanced maternal age demonstrated the highest impact on uptake of prenatal diagnosis. Further, university educational level in relation to lower educational level was associated with an increased likelihood of undergoing CUB (OR 2.30, 95% CI 2.26-2.35), AC (OR 1.54, 95% CI 1.46-1.63) and CVS (OR 2.68, 95% CI 2.44-2.93).

Conclusion

Offers of prenatal diagnosis varied considerably between counties resulting in unequal access to prenatal diagnosis for pregnant women. The intentions of the Swedish Health and Medical Services Act stating equal care for all, was thus not fulfilled.

Keywords Pregnant women, Prenatal diagnosis, Uptake, Guidelines, Antenatal Care

BACKGROUND

Antenatal care (ANC) is free of charge which almost all pregnant women in Sweden attend [1]. Most pregnant women are managed by public ANC facilities but private ANC clinics are also available. Sweden is divided into 21 counties, including 43 maternal health care areas (MHCAs). The 43 MHCAs issue medical guidelines based on national recommendations, local health care organization, and local policy related to surveillance of pregnancy [1]. For each MHCA, a senior consultant obstetrician and a senior consultant midwife are responsible for the medical guidelines. ANC in Sweden is mainly organized within the primary health system, but exceptionally it is integrated within hospital systems. Midwives working in ANC units are responsible for the monitoring of pregnant women with regard to current medical guidelines, and are responsible of referral of patients to hospital clinics when indicated. Information on prenatal diagnosis is provided by midwives in ANC, whereas prenatal screening or diagnostic procedures are generally undertaken in hospital-based clinics. In addition, midwives in ANC have to manage different

administrative systems related to provision of health care, such as keeping medical records, and entering data into the Swedish Pregnancy Register.

The Swedish Maternal Health Care Register and the Swedish Pregnancy Register

The Swedish Maternal Health Care Register (MHCR) is a national quality register where pregnant women participate on a voluntary basis by contributing with information on their pregnancy and delivery [2]. MHCR has collected data on outcomes of pregnancy, delivery, and the postpartum period since 1999. The quality of data recorded in the MHCR has previously been investigated, and show that most variables in the MHCR demonstrated good to a very good degree of coverage of data, and satisfying internal validity [3]. The MHCR was integrated in the Swedish Pregnancy Register (SPR) in January 1st 2013, in a merge of three registers involved in the different aspects of health care during pregnancy. The proportion of pregnancies registered in the MHCR was 81% and 85% during 2011 and 2012. The participation rate in the SPR during 2013 was further increased, reaching 89% of all women continuing pregnancy.

The National Board of Health and Welfare in Sweden has issued regulations concerning counselling on different methods of early prenatal screening and diagnostic procedures [4]. These regulations state that pregnant women and their partners must be offered this information at first visit in ANC. Early prenatal diagnosis is defined as prenatal screening and diagnostic procedures up to 22 weeks of gestation [5]. Prenatal screening or diagnostic procedures during the first 20 weeks of gestation include the second trimester scan usually performed at a gestational age of 18 to 20 weeks, Combined Ultrasound and Biochemical test (CUB) and invasive tests such as either Chorionic Villus Sampling (CVS) or Amniocentesis (AC). CUB is a screening test, basically used to estimate the risks of trisomy 13, 18, and 21. The CUB test is performed during the first trimester when maternal serum samples are collected followed by a nuchal translucency scan during the gestational period of 11 to 13 + 6 days [6, 7]. The combined likelihood ratios are then calculated, and when the risk of Down's syndrome is estimated to be higher than 1/200 above, the woman is offered an invasive procedure in order to obtain a certain diagnosis [8]. An invasive test may be a consequence of CUB, but may also be performed due to a known or suspected genetic condition that may be determined by DNA-PCR, CGH array or specific mutation analysis [5]. AC may be performed following 15 completed weeks, due to the increased risk of miscarriage or clubfoot, if the procedure is performed at an earlier gestational age [9].

The rationale of this study was to investigate the utilisation of prenatal diagnosis in Sweden during the study period 2011 to 2013 in relation to the different offers of prenatal screening and diagnostic procedures on a national level and comparing different counties.

Aims

The overall aim was to investigate background characteristics and pregnancy outcomes in relation to the use of prenatal screening methods and diagnostic procedures in Sweden.

The specific aims of the study were to *i)* investigate guidelines on prenatal diagnosis in the counties of Sweden, *ii)* investigate uptake of routine ultrasound examination, combined ultrasound and biochemical test (CUB), chorionic villus sampling (CVS) and amniocentesis (AC), and *iii)* background characteristics and pregnancy outcomes in relation to different prenatal screening and diagnostic procedures.

METHODS

Study design and setting

This retrospective, cross-sectional, epidemiological study analysed data on pregnancies from the Swedish Maternal Health Care Register and the Swedish Pregnancy Register from 2011 to 2013. MHCR was an independent register until 2012. MHCR was integrated into the SPR, as one of three registers when the SPR was formed in 2013. Here, SPR refers to MHCR and SPR as one entity. Inclusion criteria, for participating in the study, were being a subject included in the SPR with a date of delivery of a live or stillborn child from January 1st 2011 to December 31st 2013, and with a gestational age of 22 weeks and 0 days to 43 weeks and 0 days. Data on all pregnancies 2011 to 2013 were obtained from the SPR, comprising 284,789 women and their offspring. The participation rate of pregnant women in SPR was during 2011, 2012, and 2013, 81%, 85% and 89%, respectively. The coverage of variables in relation to county, varied from 74% to 99% during 2013. Additionally, medical guidelines regarding offers to pregnant women on prenatal screening and diagnostic procedures were collected from each Maternal Health Care Area (MHCA; N=43) in Sweden for 2011, 2012 and 2013. The guidelines during this study period were almost consistent with the exception of changes in two counties where no pregnant women previously had been offered CUB until 2011. A new guideline was introduced during 2012 in these two counties, offering all pregnant women CUB. The proportion of births in these two counties corresponds to 4% of all births in Sweden. Sweden includes 21 different

counties where the majority of counties host only one MHCA, whereas some larger cities host multiple MHCAs, as for example the area of the capital Stockholm. Results related to guidelines will be presented on county-level.

Definitions of variables

Some variables acted both as independent and dependent variables in analyses. See the descriptions below.

Independent variables

Maternal age was defined as age in years at delivery. *Parity* was defined as total number of children born (including the index pregnancy in the SPR). *Primiparity* was defined as having delivered one child, i.e. including the index pregnancy, and *multiparity* was defined as having delivered at least 2 children (in two pregnancies or more, including the index pregnancy). *Body mass index* (BMI) was calculated with the formula BMI=kg/m^2. The different BMI groups were defined in accordance with the WHO's definition of BMI: underweight: <18.50 kg/m^2; normal weight: 18.50-24.99 kg/m^2; overweight: 25.00-29.99 kg/m^2, obesity class 1: 30.00-34.99 kg/m^2, obesity class 2: 35.00-39.99 kg/m^2, and obesity class 3: ≥40.00 kg/m^2 [10]. *Level of education* was defined as elementary school, high school or university. *Employment status* was categorized into "employed", "student", "parental leave", "unemployed", "sick leave", and "other status". *Country of origin* was categorized into Sweden, other Nordic countries (Norway, Finland, Iceland, and Denmark) and Europe (excluding Sweden and other Nordic countries), Africa, Asia and other countries. The variable Alcohol screening (Alcohol Use Disorder Identification Test = AUDIT scores) was categorized in whether performed "yes" or "no". *AUDIT-score* ranged from 0 to 40 scores, and was categorized into ≤5 scores and ≥6 scores, which indicates harmful alcohol use [11]. *Self-rated health prior to pregnancy* was categorized in "very good", "good", "neither good nor poor", "poor", and "very poor". The following variables were categorized in "yes" or "no": *smoking at three months prior to pregnancy, smoking at first ANC visit, smoking at 32 weeks of gestation, use of snuff three months prior to pregnancy, use of snuff three months at first ANC, use of snuff at 32 weeks of gestation, counselling due to fear of childbirth* where fear of childbirth was defined in the SPR as a subject being referred for counselling due to fear of childbirth, *treatment of psychiatric disorder* where psychiatric disorder was defined in the SPR as either medical or psychological treatment of psychiatric disorder, or both, *combined ultrasound and biochemical test* (CUB), *chorionic villus sampling* (CVS) and *amniocentesis* (AC).

Dependent variables

The following variables were categorized into "yes" or "no": *combined ultrasound and biochemical test* (CUB), *chorionic villus sampling* (CVS), *amniocentesis* (AC), *counselling due to fear of childbirth and treatment of psychiatric disorder. Gestational age* was reported in days of gestation and presented as a continuous variable. *Mode of delivery* was categorized in "vaginal delivery", "instrumental delivery" (including delivery with vacuum extraction or forceps), and "caesarean section". Caesarean section (CS) was further categorized in "elective caesarean section" and "emergency caesarean section". *Birth weight* in grams was presented as a continuous variable.

The Regional Ethical Board at Umeå University (Umeå, Sweden) approved the study (Dno 2012-407-31M and 2014-152-32M).

Statistics

Categorical variables were analysed with frequencies and percentages. Continuous variables were presented by their mean value and standard deviation (SD), and by their median value and interquartile range (IQR). Continuous variables were tested for the assumption of normal distribution. Test of trend was analysed by Linear-by-Linear Association for investigation of linear trends over the years. Test of difference between independent groups were analysed with One-Way Anova test and independent samples t-test for parametric data, corrected for homogeneity for variance if necessary. The Pearson's Chi-Square test was used for test of difference between groups for categorical data. Level of significance was set at $p<0.05$. Odds ratios (OR) and their 95% confidence intervals (CI) were calculated in univariate and multivariable logistic regression analyses. SPSS vs. 22 and vs. 23 were used for these calculations. A Venn diagram was created to present the uptake of CUB, CVS and AC in the study sample. A figure presenting a map of Sweden was created to illustrate geographical differences in uptake of CUB, where the 21 counties were categorized into 4 groups of CUB uptake rate: less than 10%, 10 to 29.99%, 30 to 69.99% or 70% or more.

RESULTS

Offers on prenatal diagnosis in Sweden

All counties in Sweden except one had issued written guidelines concerning offers of prenatal screening methods and diagnostic procedures during the first and second trimesters of pregnancy. These guidelines remained unchanged in all counties except for two counties, during the study period. Three Swedish counties offered a routine ultrasound examination at 12 weeks of gestation for the purpose of dating and all other counties offered a second trimester scan at the gestational age of 17-20 weeks, with the exception of one county that accepted dating from week 16. CUB was offered to all pregnant women in six counties, was offered on indication advanced maternal age in nine counties, and was not offered at all in five counties. The definition of advanced maternal age as indication for CUB demonstrated a substantial variation between counties. The different cut-off-values defining an indication for offering the CUB test were: age >33 years at last menstrual period, age ≥35 years at last menstrual period, age ≥35 years at conception, age ≥35 years at the time for the CUB-test, and age ≥35 years at the estimated date of delivery. In addition, one county included "anxiety related to pregnancy" as an indication for offering CUB. All counties offered either CVS or AC as prenatal diagnostic procedures on the indications: maternal age ≥35 years, increased risk for chromosomal aberration following CUB, or second trimester serum screening, or familial genetic condition. Three counties offered AC only if CUB had previously been performed and indicated an increased risk. During 2013, the uptake of CUB varied between the counties from 2.2% to 80.3%, (Table 1). Figure 1 shows a map of Sweden presenting the 21 counties and their uptake of CUB categorized into four levels. The lowest uptake rate, i.e. uptake less than 10%, corresponds to counties where no pregnant women were offered CUB. Pregnant women, living in any of the counties where no women were offered CUB, could still have undergone CUB but if so, privately and at their own expense.

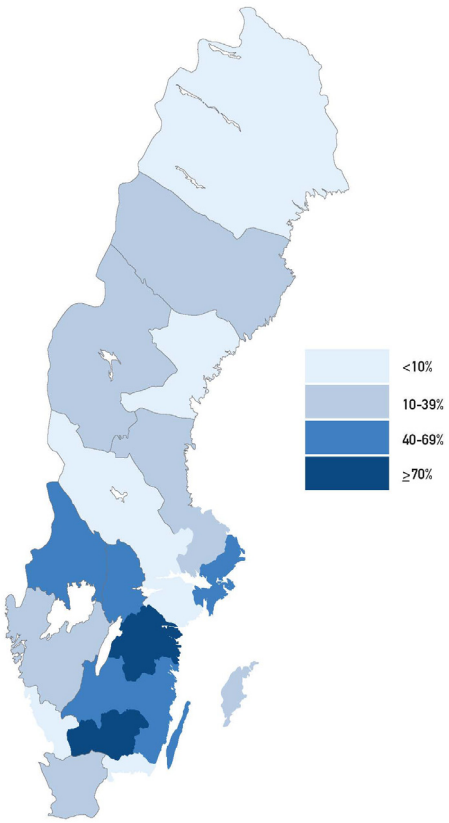

Figure 1. Map of Sweden indicating the 21 counties and Combined Ultrasound and Biochemical test (CUB) uptake, 2013.

Table 1. Uptake of Combined Ultrasound and Biochemical test (CUB) per County (N=21) 2011 to 2013

County	CUB			Proportions[a]
	2011	2012[b]	2013	2013
	%	%	%	%
1	41.0	47.4	53.2	26.1
2	18.4	19.5	21.4	17.0
3	26.4	27.8	30.1	13.8
4	81.4	78.9	80.3	4.4
5	23.7	25.0	24.9	3.5
6	64.9	66.6	66.9	3.4
7	6.7	7.9	7.0	2.9
8	59.5	61.6	63.4	2.9
9	2.4	3.0	2.7	2.7
10	5.1	5.1	3.9	2.5
11	10.4	11.7	11.0	2.5
12	6.4	9.3	9.7	2.4
13	48.9	56.3	60.9	2.4
14	1.1	1.7	2.2	2.2
15	5.3	6.7	8.8	2.1
16	13.1	13.7	12.6	2.1
17	2.9	28.8	66.7	2.1
18	4.2	18.9	75.1	1.9
19	2.0	3.9	5.3	1.3
20	13.3	16.2	15.1	1.1
21	12.5	14.6	14.2	0.5
Total	29.8	32.5	36.2	100

[a] Proportions of births per county in relation to the total number of births in Sweden 2013 (N=113,593)

[b] County no 17 and no 18 changed their guidelines of prenatal diagnosis during 2012

The study population

The study population included 284,789 pregnant women, and the distribution of participants per year was 30.9% (2011), 33.7% (2012) and 35.3% (2013). Background characteristics for the study population are presented in Table 2. Mean age and mean body mass index (BMI) were 30.24 years and 24.79 kg/m^2, respectively. Mean age and body mass index of primiparous and multiparous women were 28.83 years and 31.72 years, and 24.34 kg/m^2 and 25.14 kg/m^2, respectively (Table 2). For multiparous women, the variable maternal age was normally distributed 2012 and 2013 (Table 2). For primiparous women who had undergone CUB-test the variable maternal age was normally distributed (Table 4). All other continuous variables demonstrated skewness to some degree. Almost all pregnant women were examined with a routine ultrasound scan during pregnancy (97.6%), and the overall proportions of women examined with CUB, CVS or AC were 33.0%, 1.1% and 2.6% (Table 3). The percentage of women examined with CUB increased significantly during the study period from 29.8% in 2011 to 36.2% in 2013 ($p<0.001$) (Table 3). The number of pregnant women, who were examined with CUB, CVS or AC, or any combinations of these procedures, was in total 98,697, which corresponds to 33.4% of all women and is presented in a Venn diagram (Figure 2). Of all

pregnant women who were examined with CUB, 1.1 % (n=1,252) thereafter underwent CVS, and 2.7 % (n=2,493) underwent AC after CUB. Of all women who were examined with CVS (n=2,970), 42.2% had undergone CUB prior to CVS. Of all women who were examined with AC (n=7,279), 34.2% had undergone CUB prior to AC.

Table 2. Background characteristics and pregnancy outcomes in the Swedish Pregnancy Register 2011 to 2013 (N=284,789)

Variable	Total N=284,789		2011 n=88,140		2012 n=96,043		2013 n=100,606		Test of difference[a]
	n	%	n	%	n	%	n	%	
Maternal age[b], primiparous women (years)									
Mean (SD)[c]	28.83 (5.12)		28.78 (5.17)		28.82 (5.14)		28.87 (5.07)		0.053
Min-max	13.49-56.30		13.52-52.64		13.78-56.30		13.49-52.89		
Median (IQR)[d]	28.64 (7.07)		28.66 (7.08)		28.59 (7.05)		28.67 (7.04)		
Maternal age[b], multiparous women (years)									
Mean (SD)[c]	31.72 (4.90)		32.29 (4.89)		32.21 (4.90)		32.16 (4.89)		<0.001
Min-max	15.00-57.00		17.07-53.25		16.41-54.47		15.67-57.34		
Median (IQR)[d]	32.30 (6.88)		32.41 (6.91)		32.28 (6.84)		32.23 (6.89)		
Maternal age[b] in age-groups (years)									
<20	3,976	1.4	1,369	1.6	1,319	1.4	1,288	1.3	
20-24	38,832	13.6	11,990	13.6	13,222	13.8	13,611	13.5	
25-29	84,129	29.5	25,578	29.0	28,393	29.6	30,158	30.0	
30-34	95,772	33.6	29,463	33.4	32,243	33.6	34,066	33.9	
35-39	50,717	17.8	16,215	18.4	17,010	17.7	17,492	17.4	
40-44	10,705	3.8	3,323	3.8	3,625	3.8	3,757	3.7	
>44	583	0.2	167	0.2	213	0.2	203	0.2	
Body mass index (kg/m^2)									
Mean (SD)[c]	24.79 (4.65)		24.75 (4.62)		24.82 (4.67)		24.81 (4.66)		0.002
Min-max	13.03-71.63		13.82-62.06		13.63-67.22		13.03-71.63		
Median (IQR)[d]	23.80 (5.00)		23.74 (5.41)		23.81 (5.45)		23.81 (5.52)		
<18.5	6,838	2.5	2,044	2.4	2,328	2.5	2,466	2.5	
18.5-24.99	163,856	59.2	50,787	59.7	55,203	58.9	57,866	58.9	
25-29.99	70,440	25.4	21,478	25.3	23,870	25.5	25,092	25.5	
30-34.99	25,166	9.1	7,526	8.8	8,573	9.2	9,067	9.2	
35.39.99	7,899	2.9	2,374	2.8	2,734	2.9	2,791	2.8	
≥40	2,759	1.0	836	1.0	969	1.0	954	1.0	
Educational level									
Elementary school	20,860	8.7	6,662	9.4	6,870	8.5	7,328	8.4	<0.001
High school	95,564	40.0	27,821	39.4	32,660	40.3	35,083	40.1	
University	122,623	51.3	36,155	51.2	41,432	51.2	45,036	51.5	
Main occupation									
Employed	195,880	70.3	59,890	70.3	66,622	70.5	69,368	70.1	<0.001
Student	31,021	11.1	9,697	11.4	10,364	11.0	10,960	11.1	
Parental leave	20,469	7.3	6,082	7.1	6,911	7.3	7,475	7.5	
Unemployed	15,163	5.4	4,955	5.8	4,996	5.3	5,212	5.3	
Sick leave	4421	1.6	1,241	1.5	1,557	1.6	1,623	1.6	
Other	11,686	4.2	3,300	3.9	4,013	4.2	4,373	4.4	
Country of birth									
Sweden	221,398	79.4	70,376	81.8	74,187	78.9	76,835	77.8	<0.001
Other Nordic countries[e]	2,374	0.8	613	0.8	832	0.8	929	0.8	
Europe[f]	12,861	4.6	3,486	4.0	4,481	4.8	4,900	5.0	
Africa	10,782	3.9	2,780	3.2	3,658	3.9	4,344	4.4	
Asia	25,597	9.2	6,886	8.0	8,976	9.5	9,735	9.9	
Other	5,902	2.1	1,917	2.2	1,940	2.1	2,045	2.1	
Smoking 3 months prior to pregnancy	38,854	13.8	12,134	13.9	13,285	14.0	13,435	13.5	0.004
Smoking at first ANC[g] visit	15,874	5.6	5,062	5.8	5,475	5.7	5,337	5.4	<0.001
Smoking at 32 weeks of gestation	11,990	4.2	3,923	4.5	4,133	4.3	3,934	3.9	<0.001
Use of snuff 3 months prior to pregnancy	9,954	3.5	2,530	2.9	3,506	3.7	3,918	3.9	<0.001
Use of snuff at first ANC[g] visit	2,858	1.0	793	0.9	945	1.0	1,120	1.1	<0.001
Use of snuff at 32 weeks of gestation	1,721	0.6	548	0.6	561	0.6	612	0.6	0.572
Alcohol screening (AUDIT)[h]	245,544	88.1	74,712	86.7	81,408	86.7	89,424	90.6	<0.001

AUDIT-score[i]									
Mean (SD)[c]	2.19 (2.19)		2.28 (2.22)		2.20 (2.22)		2.09 (2.15)		
Min-max	0-40		0-39		0-40		0-40		
Median (IQR)[d]	2.00 (2)		2.00 (2)		2.00 (2)		2.00 (3)		
≤5p	229,854	94.0	69,110	93.6	76,327	93.8	84,417	94.4	<0.001
≥6p	14,751	6.0	4,704	6.4	5,044	6.2	5,003	5.6	
Self-rated health prior to pregnancy	241,854	84.9	70,633	80.1	82,594	86.0	88,627	88.1	
Very good	72,321	29.9	19,838	28.1	24,472	29.6	28,011	31.6	<0.001
Good	141,251	58.4	41,299	58.5	48,441	58.6	51,511	58.1	
Neither good nor poor	20,425	8.4	6,793	9.6	6,962	8.4	6,670	7.5	
Poor	6,325	2.6	2,174	3.1	2,197	2.7	1,954	2.2	
Very poor	1,532	0.6	529	0.7	522	0.6	481	0.5	
Counselling due to fear of childbirth	21,595	7.6	6,518	7.5	7,186	7.5	7,891	7.9	0.001
Treatment of psychiatric disorder	17,724	6.3	5,122	5.9	6,061	6.4	6,541	6.5	<0.001
Gestational age (days)									
Mean (SD)[c]	278.0 (13.8)		278.0 (13.9)		277.8 (13.9)		278.1 (13.7)		<0.001
Min-max	154-301		155-301		154-301		154-301		
Median (IQR)[d]	280.00 (13.00)		280.00 (13.00)		280.00 (13.00)		280.00 (13.00)		
Mode of delivery	283,660	99.6	87,915	99.7	95,594	99.5	100,151	99.5	
Vaginal	217,898	76.8	67,277	76.5	73,333	76.7	77,288	77.2	<0.001
Instrumental	19,177	6.8	6,208	7.1	6,616	6.9	6,353	6.3	
Caesarean section	46,585	16.4	14,430	16.4	15,645	16.4	16,510	16.5	
Caesarean section (CS)									
Elective CS[j]	20,272	43.6	6,321	43.9	6,718	43.0	7,233	43.9	0.193
Emergency CS[j]	26,214	56.4	8,085	56.1	8,897	57.0	9,232	56.1	
Birth weight (grams)[k]									
Mean (SD)[c]	3542 (556)		3540 (557)		3543 (556)		3543 (556)		0.352
Min-max	300-6640		300-6050		305-6270		300-6640		
Median (IQR)[d]	3550 (670)		3550 (675)		3550 (674)		3550 (670)		

[a] Test of difference between years using One-Way Anova test on numeric variables, and Pearsons's Chi-Square test for categorical variables
[b] Maternal age at delivery
[c] SD = Standard Deviation
[d] IQR = Interquartile Range
[e] Other Nordic countries includes Norway, Finland, Iceland and Denmark
[f] The Nordic countries are excluded
[g] Antenatal care
[h] Assessment of use of alcohol prior to pregnancy with screening instrument Alcohol Use Disorder Identification Test (AUDIT)
[i] AUDIT score ranging from 0 to 40
[j] Caesarean section
k Singletons exclusively included in analysis

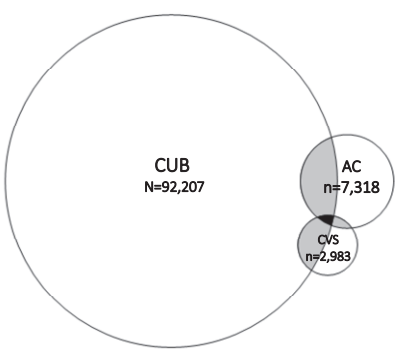

Figure 2. Pregnant women that were examined with CUB, AC and CVS

Table 3. Uptake of routine ultrasound examination, Combined Ultrasound and Biochemical test (CUB), Chorionic Villus Sampling (CVS) and Amniocentesis (AC) during 2011 to 2013, and test of trend[a]

Variable	Total N=284,789		2011 n=88,140		2012 n=96,043		2013 n=100,606		Trend[a]
	n	%	n	%	n	%	n	%	
Ultrasound	281,562	98.9	85,561	97.1	97,500	99.6	100,310	99.7	
Yes	274,899	97.6	83,549	97.6	93,386	97.6	97,964	97.7	0.716
No	6,663	2.4	2,012	2.4	2,314	2.4	2,337	2.3	
CUB	278,230	98.0	84,827	96.2	94,900	98.8	99,503	98.9	
Yes	92,207	33.0	25,316	29.8	30,826	32.5	36,065	36.2	<0.001
No	187,023	67.0	59,511	70.2	64,074	67.5	63,438	63.8	
CVS	280,898	98.6	85,308	96.8	95,465	99.4	100,125	99.5	
Yes	2,983	1.1	868	1.0	927	1.0	1,188	1.2	<0.001
No	277,915	98.9	84,440	99.0	94,538	98.8	98,937	98.8	
AC	280,667	98.6	85,213	99.3	95,395	99.3	100,059	99.5	
Yes	7,318	2.6	2,500	2.9	2,473	2.6	2,345	2.3	<0.001
No	273,349	97.4	82,713	97.1	92,922	97.4	97,714	97.7	

[a] Test of trend by Linear-by-Linear Association

Mean age for primiparous women who underwent CUB, CVS or AC was 31.34, 33.79 and 33.65 years, respectively (Table 4). Overall mean age for pregnant women who had not been examined with CUB, CVS or AC was 28.84 (defined as "all others" in Table 4), where the mean age for primiparous and multiparous women in this category was 27.09 years and 30.29 years, respectively. BMI for pregnant women who had undergone CUB, CVS or AC was 24.40, 24.10 and 24.94, respectively, whereas BMI for pregnant women who had not undergone CUB, CVS or AC ("all others") was 24.99. There was a statistically significant difference in BMI between those who underwent CUB and "all others" (p-value <0.001) (Table 4). Pregnant women who underwent CUB, CVS or AC reported being employed in significantly higher proportions (80.3%, 87.0% and 77.8%, respectively), vs. 65% for women who had not undergone CUB, CVS or AC (p-value <0.001). Information on country of birth was available for almost all participants (Table 2). Sweden as country of birth was reported by 79.4% of all pregnant women (Table 2). Pregnant women who had undergone CUB, CVS and AC, reported Sweden as country of birth in 84.5%, 85.4% and 81.8% of the cases, respectively. The corresponding figure for pregnant women who had not been exposed to CUB, CVS or AC was 76.7%. That means that a significantly lower proportion of women who were born outside of Sweden was examined by CUB, CVS and AC (p-value <0.001) (Table 4). A proportion of 35.2% of women with a Nordic origin were exposed to CUB. The corresponding figures for women born in Europe, Africa, and Asia were 31.5%, 11.8% and 24.5% respectively. Smoking was reported to a significantly lower degree (p-value <0.001) at all three check points, i.e. 3 months prior to pregnancy, at first antenatal visit and at gestational age of 32 weeks, by women who had undergone CUB compared to those who had not been examined by CUB, CVS or AC, i.e. "all others" (Table 4).

Women who had been examined by CUB, CVS or AC reported having received counselling due to fear of childbirth in 9.7%, 10.9% and 10.2% of cases, respectively. Women who had not been examined with CUB, CVS or AC reported having received counselling due to fear of childbirth in a significantly lower proportion (6.5%; p-value <0.001) (Table 4). There was no significantly difference between the group of women who had undergone CUB and women included in the group "all others" regarding gestational age at delivery (Table 4). The overall proportion of CS in the study group was 16.4% (Table 2). For pregnant women who had undergone CUB, CVS and AC, the prevalence of CS were 19.1%, 24.3% and 24.3%, respectively, and the corresponding figure for "all others" was significantly lower 14.8% (p-value <0.001) (Table 4). If caesarean section had been performed, the proportions of those who underwent elective CS or emergency CS were as follows; women who had undergone CUB, 49.3% and 50.7%, women who had undergone AC, 51.7% and 48.3% and women who had undergone CVS, 58.7% and 41.3% respectively. The corresponding figures for women included in the group "all others" were 39.1% (elective CS) and 60.9% (emergency CS), (Table 4). The odds ratio for undergoing CUB at a maternal age of 35 years or older, was highly increased (4.36; 95% CI 4.28-4.45). When the OR was adjusted for educational level the OR still remained increased (4.00; 95% CI 3.91-4.08). Table 5 presents univariate and multivariable logistic regression analyses for the uptake of CUB in relation to specific background characteristics. Educational level demonstrated a strong impact on the likelihood of being examined with a CUB test. Women under the age of 35 years, having attended university, had an Adjusted Odds Ratio (AOR) of 1.79 (95% Adjusted Confidence Interval (ACI) 1.75-1.83) for undergoing CUB (Table 5). The corresponding figure for women 35 years or older who had attended university was AOR 1.53 (95% ACI 1.47-1.61) (Table 5). Pregnant women with a BMI of 25 or more, women who were unemployed, women who were born outside of Sweden and women who reported ongoing smoking at their first visit at ANC demonstrated a decreased AOR for undergoing CUB (Table 5). Women under the age of 35 years who had received counselling due to fear of childbirth had an increased AOR of 1.38 (95% ACI 1.32-1.45) for undergoing CUB, whereas the corresponding figure for women 35 years or older was somewhat lower (1.27; 95% ACI 1.18-1.28). Women in both age groups, having received treatment for psychiatric disorder, demonstrated a small but statistically significant increased AOR for undergoing CUB (Table 5). Maternal age demonstrated the highest impact on the likelihood of undergoing invasive prenatal diagnosis (AC: COR 7.97; 95% CI 7.58-8.38, and CVS: COR 6.72; 95% CI 6.23-7.24). Further, women who had achieved an educational level corresponding to university had an increased likelihood of undergoing AC (COR 1.54; 95% CI 1.46-1.62) and CVS (2.68; 95% CI 2.45-2.92), in relation to women with a lower educational level. Their increased odds ratios for AC and CVS remained unchanged after adjusting for maternal age (AC: AOR 1.54; 95% ACI 1.46-1.62, and CVS: AOR 2.68; 95%

ACI 2.45-2.92). Additionally, pregnant women who had received counselling due to fear of childbirth demonstrated a higher likelihood of undergoing AC or CVS (AC: COR 1.39; 95% CI 1.29-1.50, and CVS: COR 1.49; 95% CI 1.32-1.67), in comparison to those who had not been counselled for fear of childbirth. When adjusted for age and educational level the likelihood remained significantly increased for AC (AOR 1.14; 95% ACI 1.04-1.24) and CVS (AOR 1.15; 95% ACI 1.01-1.31). A decreased likelihood of undergoing AC or CVS was demonstrated for pregnant women who reported country of birth outside of Sweden, compared to those who were born in Sweden (AC: COR 0.85; 95% CI 0.80-0.91, and CVS: COR 0.66; 95% CI 0.59-0.73). When adjusted for age and educational level the odds ratios remained significantly decreased (AC: AOR 0.88; 95% ACI 0.82-0.95, and CVS: AOR 0.81; 95% ACI 0.72-0.91).

Table 4. Background characteristics and pregnancy outcomes in relation to prenatal screening or diagnostic procedures in the Swedish Pregnancy Register 2011 to 2013 (N=284,789)

Variable	CUB[a] n=92,207		CVS[b] n=2983		AC[c] n=7318		All others[d] n=186,092		Test of difference[e]
	n	%	n	%	n	%	n	%	
Maternal age[f], primiparous women (years)									
Mean (SD)[g]	31.34 (5.17)		33.79 (5.74)		33.65 (6.11)		27.09 (4.58)		<0.001
Min-max	15.09-56.30		17.29-49.03		16.74-49.83		13-54		
Median (IQR)[h]	31.34 (7.32)		34.41 (8.38)		34.92 (9.15)		27.51 (6.41)		
Maternal age[f], multiparous women (years)									
Mean (SD)[g]	34.45 (4.45)		36.87 (4.65)		37.13 (4.66)		30.29 (4.52)		<0.001
Min-max	16.41-55.34		19.10-51.76		16.41-48.68		15-57		
Median (IQR)[h]	34.97 (5.72)		37.58 (5.66)		37.82 (5.45)		30.87 (6.07)		
Maternal age[f] in age-groups (years)									
<20	388	0.4	8	0.3	23	0.3	3,566	1.9	
20-24	5,863	6.4	99	3.3	313	4.3	32,702	17.6	
25-29	17,617	19.1	300	10.1	733	10.0	65,926	35.4	
30-34	31,792	34.5	649	21.8	1,314	18.0	62,944	33.8	
35-39	30,179	32.7	1,262	42.3	3,148	43.0	17,676	9.5	
40-44	6,093	6.6	628	21.1	1,675	22.9	2,991	1.6	
>44	270	0.3	36	1.2	109	1.5	211	0.1	
Body mass index (kg/m^2)									
Mean (SD)[g]	24.40 (4.34)		24.10 (4.10)		24.94 (4.52)		24.99 (4.80)		<0.001
Min-max	13.82-56.65		15.24-51.31		15.24-50.69		13.03-71.63		
Median (IQR)[h]	23.45 (5.0)		23.18 (5.0)		24.01 (5.0)		23.95 (6.0)		
<18.5	1,965	2.2	52	1.8	121	1.7	4,766	2.6	
18.5-24.99	56,723	63.2	1,918	66.3	4,140	58.2	103,359	57.2	
25-29.99	21,639	24.1	663	22.9	1,926	27.1	47,160	26.1	
30-34.99	6,863	7.6	195	6.7	652	9.2	17,741	9.8	
35.39.99	1,992	2.2	48	1.7	203	2.9	5,744	3.2	
≥40	629	0.7	18	0.6	68	1.0	2,071	1.1	
Educational level									
Elementary school	3,242	4.1	69	2.7	334	5.3	17,353	11.2	<0.001
High school	24,324	31.1	608	23.7	2,078	33.1	69,523	44.8	
University	50,763	64.8	1,887	73.6	3,869	61.6	68,302	44.0	
Main occupation									
Employed	72,519	80.3	2,439	83.7	5,582	77.8	118,371	65.0	<0.001
Student	6,467	7.2	146	5.0	524	7.3	24,121	13.3	
Parental leave	5,059	5.6	149	5.1	459	6.4	15,002	8.2	
Unemployed	3,320	3.7	78	2.7	294	4.1	11,601	6.4	
Sick leave	1,306	1.4	36	1.2	119	1.7	3,009	1.7	
Other	1,610	1.8	66	2.3	194	2.7	9,897	5.4	
Country of birth									
Sweden	76,276	84.5	2,482	85.4	5,876	81.8	139,881	76.7	<0.001
Other Nordic countries[i]	904	1.0	31	1.1	74	1.0	1,406	0.8	
Europe[i]	3,971	4.4	102	3.5	332	4.6	8,617	4.7	
Africa	1,243	1.4	37	1.3	127	1.8	9,438	5.2	
Asia	6,132	6.8	196	6.7	590	8.2	18,955	10.4	
Other	1,727	1.9	57	2.0	180	2.5	4,007	2.2	

Smoking 3 months prior to pregnancy	9,583	10.5	229	7.7	751	10.3	28,659	15.6	<0.001
Smoking at first ANC[k] visit	3,445	3.8	76	2.6	347	4.8	12,144	6.6	<0.001
Smoking at 32 weeks of gestation	2,527	2.8	48	1.6	289	4.0	9,238	5.0	<0.001
Use of snuff 3 month prior to pregnancy	2,493	2.7	64	2.2	213	2.9	7,268	3.9	<0.001
Use of snuff at first ANC visit	646	0.7	22	0.7	85	1.2	2,134	1.2	<0.001
Use of snuff at 32 weeks of gestation	385	0.4	13	0.4	41	0.6	1,303	0.7	<0.001
Alcohol screening (AUDIT)[l]	81,686	90.3	2,568	88.4	6,313	86.3	158,335	87.0	<0.001
AUDIT-score[m]									
Mean (SD)	2.34 (1.96)		2.26 (1.74)		2.12 (1.90)		2.11 (2.32)		
Min-max	0-38		0-18		0-29		0-40		
Median (IQR)[h]	2.00 (2)		2.00 (2)		2.00 (2)		2.00 (3)		
≤5p	76,786	94.5	2,462	96.3	6,012	95.7	82,067	94.6	<0.001
≥6p	4,485	5.5	95	3.7	270	4.3	4,703	5.4	
Self-rated health prior to pregnancy									
Very good	25,990	33.0	834	32.5	1,887	30.5	44,643	28.3	<0.001
Good	44,563	56.6	1,433	55.9	3,489	56.5	93,611	59.4	
Neither good nor poor	5,877	7.5	217	8.5	583	9.4	14,047	8.9	
Poor	1,817	2.3	64	2.5	187	3.0	4,334	2.7	
Very poor	440	0.6	15	0.6	34	0.6	1,056	0.7	
Counselling due to fear of childbirth	8,900	9.7	324	10.9	745	10.2	12,023	6.5	<0.001
Treatment of psychiatric disorder	6,002	6.5	185	6.3	533	7.3	11,275	6.1	<0.001
Gestational age (days)									
Mean (SD)[g]	278.0 (13.7)		276.6 (15.0)		276.5 (15.4)		278.0 (13.8)		0.326
Min-max	154-301		158-300		157-301		154-301		
Median (IQR)[h]	280.0 (13.0)		279.0 (13.0)		279 (15.0)		280 (13.00)		
Mode of delivery									
Vaginal	6,885	73.9	2,079	70.2	5,133	70.3	145,486	78.5	<0.001
Instrumental	6,376	6.9	163	5.5	392	5.4	12,468	6.7	
Caesarean section	17,574	19.1	721	24.3	1,772	24.3	27,405	14.8	
Caesarean section (CS) [n]									
Elective CS[n]	8,650	49.3	297	58.7	916	51.7	10,700	39.1	<0.001
Emergency CS[n]	8,893	50.7	422	41.3	855	48.3	16,639	60.9	
Birth weight (grams)[o]									
Mean (SD)[g]	3549 (552)		3531 (585)		3510 (620)		3539 (557)		0.001
Min-max	310-6270		400-5710		370-5776		300-6640		
Median (IQR)[h]	3560 (665)		3555 (686)		3548 (706)		3545 (680)		

[a] CUB = Combined Ultrasound and Biochemical test
[b] CVS = Chorionic Villus Sampling
[c] AC = Amniocentesis
[d] All others = Pregnant women who did not undergo any of the prenatal diagnostic procedures CUB, CVS or AC
[e] Test of difference between the two groups; pregnant women who underwent CUB and "all others" using t-test for continuous variables and Pearson's Chi-Square test for categorical variables
[f] Maternal age at delivery
g SD = Standard Deviation
h IQR = Interquartile Range
i Other Nordic countries includes Norway, Finland, Iceland and Denmark
j The Nordic countries excluded
k Antenatal care
l Assessment of use of alcohol prior to pregnancy with screening instrument Alcohol Use Disorder Identification Test (AUDIT)
m AUDIT score range from 0 to 40
n Caesarean section
o Singletons exclusively included in analysis

Table 5. Univariate and multivariable logistic regression analysis for undergoing Combined Ultrasound and Biochemical test (CUB) in relation to maternal age divided into two age groups and to specified background characteristics

Variable	Maternal age <35 years				Maternal age ≥35 years			
	Crude OR	CI 95%	Adjusted OR*	Adjusted CI 95%	Crude OR	CI 95%	Adjusted OR*	Adjusted CI 95%
Educational level								
Elementary school, high school	1		1		1		1	
University level	2.03	1.98-2.07	1.79	1.75-1.83	1.86	1.79-1.93	1.53	1.47-1.61
Body mass index (kg/m^2)								
<25	1		1		1		1	
≥25	0.75	0.73-0.76	0.84	0.82-0.86	0.65	0.63-0.68	0.76	0.73-0.80
Main occupation								
Employed, student, parental leave	1		1		1		1	
Unemployed, sick leave, other	0.51	0.49-0.53	0.70	0.67-0.74	0.46	0.44-0.49	0.64	0.59-0.70
Country of birth								
Sweden	1		1		1		1	
Other	0.60	0.58-0.61	0.76	0.74-0.79	0.55	0.53-0.57	0.74	0.70-0.78
Smoking at first visit at antenatal care								
No	1		1		1		1	
Yes	0.62	0.59-0.65	0.87	0.82-0.92	0.59	0.54-0.64	0.74	0.66-0.84
Self-rated health prior to pregnancy								
Very good and good	1		1		1		1	
Poor and very poor	0.85	0.74-0.98	0.96	0.82-1.13	0.62	0.50-0.76	0.80	0.63-1.02
Counseling due to fear of childbirth								
No	1		1		1		1	
Yes	1.41	1.36-1.46	1.38	1.32-1.45	1.40	1.32-1.48	1.27	1.18-1.28
Treatment of psychiatric disorder								
No	1		1		1		1	
Yes	1.03	0.99-1.08	1.15	1.09-1.22	1.04	0.98-1.11	1.16	1.05-1.28

*Adjusted for all other variables included in the analysis

DISCUSSION

The aim of this study was to make a national survey on guidelines concerning offers on prenatal diagnosis in Sweden. Further, we aimed to investigate background characteristics and pregnancy outcomes in relation to the uptake of different prenatal diagnostic methods. During the study period of 2011 to 2013 in Sweden there was an absence of a national consensus regarding guidelines on offers of prenatal diagnosis. The Swedish law states that all pregnant women should be offered information on prenatal diagnosis [4]. However, the opportunities of undergoing different prenatal screening or diagnostic procedures were not equally distributed during the time period under study among Swedish counties. On a national level, the uptake of the second trimester scan, CVS and AC was relatively stable during the study period whereas the uptake of CUB increased from 29.8%, 2011 to 36.2% in 2013. A Danish study performed 2008, shows a sharp decline in the uptake of invasive prenatal diagnosis when implementing screening programs offering CUB [12]. A study exploring determinants of participating in the first trimester combined test shows that advanced maternal age is the primary indication and has the highest impact for uptake of CUB [13]. As expected, our study displayed

increased maternal age as the factor with the highest impact on whether pregnant women were examined with a CUB test. Further, educational level and country of birth were also significant background factors for women's utilization of CUB. A study investigating effects of knowledge, education and experience of first trimester screening shows that women with a university education have a higher degree of knowledge of first trimester screening [14]. A Swedish study from 2012, exploring the effects of a public video aiming for an informed choice in relation to exposure to second trimester ultrasound, shows that women with college or university educational level were more likely to make an informed choice [15]. In our study women who had achieved a university education were more likely to undergo the CUB test, and the effect of educational level was more pronounced for women younger than 35 years of age in comparison to women 35 years or older. It is likely that higher education implicates a higher ability to gain, interpret and use information on different health offers, health promotion or risk factors. Ethnicity in relation to uptake of prenatal diagnosis has been investigated in several previous studies [16-18]. A register-based study in the Netherlands shows that women with a North-African ethnic origin have the lowest participation rate in prenatal screening for Down's syndrome, only 8% participation rate compared to the higher rate for women with a Dutch (28%) or other Western origin (33%) [16]. Also, an Australian study demonstrates that ethnicity is strongly associated with the uptake of prenatal diagnosis [17]. Women with Caucasian ethnicity were more likely to utilize prenatal diagnosis than other women. The proportion of screening was significantly lower for women of aboriginal origin [17]. It has been reported that Asian women living in the United Kingdom are less likely than white women to be offered and undergo screening for Down's syndrome [18]. Our study showed that women, 35 years or older and with a country of birth outside of Sweden presented a 45% decreased likelihood of undergoing CUB. The lowest uptake was demonstrated by women born in Africa. Lower uptake of prenatal diagnosis in minority ethnic groups and among socioeconomically disadvantaged women, has been shown to reflect lower rates of informed choice rather than more negative attitudes towards screening [19]. Our study was not able to investigate possible effects of language barriers for pregnant women with no or little skills in Swedish to make an informed choice. In our study, country of birth had a somewhat higher impact on utilization of CUB than on utilization of CVS or AC. This might be explained by the difficulty to inform about risk evaluation and by providing pregnant women with correct and information thus facilitating for making an informed choice. Pregnant women who had received counselling due to fear of childbirth utilized prenatal diagnosis to a higher degree than other women. To our knowledge, association between fear of childbirth and utilization of prenatal diagnosis has not previously been investigated. It seems likely that a higher level of anxiety could be manifested both as fear of childbirth as well as an increased concern related to the pregnancy resulting in increased number of medical procedures.

During the study period, the SPR did not include data on Non-Invasive Prenatal testing (NIPT). This method is based on analysis of cell-free fetal DNA in maternal blood [20]. In Sweden, NIPT is currently offered only in a few counties and strictly on specific indications. However, this method is accessible on the pregnant woman's own expense.

Methodological considerations

During the study period, the Swedish Pregnancy Register demonstrated a satisfactory coverage of pregnancies and moreover, all counties of Sweden are represented in the SPR. Data in the Swedish Medical Birth Register for 2012, demonstrate a mean maternal age, for primiparous women, of 28.4 years, and a mean BMI (all pregnant women) of 24.8 [21], and the corresponding figures in the SPR 2012, were 28.8 (years) and 24.8 (BMI), respectively. These results indicate that data in SPR are very similar to data in the Swedish Medical Register that is a compulsory health register demonstrating an almost complete coverage of pregnant women in Sweden. The validity of data in the SPR has previously been investigated and most variables demonstrate good internal validity and coverage [3]. However, the validity check also revealed that the absolute numbers of invasive prenatal diagnosis such as CVS and AC are underestimated [3]. The SPR does not include information on pregnancies with a gestational age of less than 23 weeks of gestation. Therefore, an additional limitation of this study was that different frequencies of prenatal diagnosis could not be established for this category of pregnant women that may have terminated their pregnancies.

CONCLUSIONS

Offers of prenatal diagnostic procedures varied considerably between counties in Sweden. Maternal age, as expected, demonstrated the strongest association with the uptake of CUB, AC and CVS. Further, educational level was a strong predictor of uptake of prenatal diagnosis. These circumstances result in an unequal access of prenatal diagnostic tests for pregnant women. The intentions of the Swedish Health and Medical Services Act stating that equal care should be provided for all, was thus not fulfilled. Expecting couples should be offered the same opportunities on prenatal diagnosis nationally.

COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

KP, IM, ML, and MP designed the study. KP, IM and ML performed the analyses. The interpretation of results, comments on the manuscript draft were done by all authors. All authors read and approved the final version of the paper.

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IV

"The computer deprives me of my time with patients" – Swedish midwives' experiences in antenatal care

Kerstin Petersson[1§], Margareta Persson[2], Ingrid Mogren[1*]

ABSTRACT

Objective

This overall aim of the study was to investigate the current work situation for midwives working at antenatal care clinics with the specific aim *i)* to explore straining and supporting factors affecting the work situation and *ii)* to explore midwives' experiences with providing information on prenatal diagnosis to expecting parents.

Design

A qualitative study design was applied using content analysis. Data were obtained using semi-structured individual telephone interviews.

Setting

The study recruited 15 participants varying in age and work experience and working in different antenatal care settings.

Findings

The overarching theme "Responsibility is rewarding and demanding" emerged during analyses. In general, midwives enjoyed their work in antenatal care. Work load was reported as manageable, although high. Clinical guidelines and continuing education, and collaboration between health professionals in the chain of care of the pregnant woman, were underpinning the work. Administrative work load was perceived as strenuous. The midwives believed that they needed assistants who could help them with non-specialised work

[1] Department of Clinical Sciences, Obstetrics and Gynecology, Umeå University, 901 87 Umeå, Sweden

[2] Department of Nursing, Umeå University, Umeå, Sweden

* These authors contributed equally to this work.

§ Corresponding author

tasks. Informing expecting parents about prenatal diagnosis was experienced as challenging.

Implications for practice

Work-related stress for midwives could be reduced by decreasing their administrative work load and by providing them with assistants who can help with non-specialised work tasks. In addition, midwives could improve their work conditions and the service they provide by using evidence-based health care, receiving continuing education, and using up-dated clinical guidelines to reflect advancements in antenatal care. New pedagogical tools need to be developed that will help midwives more effectively provide expecting parents, irrespective of their pre-understandings, with information about prenatal diagnosis.

Keywords: Midwife, Antenatal Care, Work condition, Prenatal diagnosis

Highlights

- Midwives working in Swedish ANC overall value their work very positively.
- Clinical guidelines and continuing education are supportive factors for clinical work.
- ANC administrative work is considered strenuous and deducts time from encounters with patients.
- Informing expecting parents on prenatal diagnosis is challenging.

INTRODUCTION

Antenatal Care in Sweden

In Sweden, around 110,000 children are born each year (1) and almost all pregnant women attend antenatal care (ANC). ANC is offered as a free service through the public primary health care system; however, some ANC is provided through the private sector or is located within hospitals (2). A national policy document providing recommendations for ANC on organisation, assignments, and clinical guidelines was collaboratively prepared by the antenatal care and the obstetrics health professional associations – the Swedish Association of Midwives and the Swedish Society of Obstetrics and Gynaecology (3). Each of the 21 counties in Sweden includes one or more Maternal Health Care Areas (MHCA) – i.e., the geographical catchment area of a specific hospital. The MHCA have an antenatal consultant obstetrician (ACO) and an antenatal care coordinator midwife (ACC) responsible for providing local guidelines, continuing education of antenatal care for physicians and midwives, assessment of quality issues, statistics, and follow-up (3). The Swedish national guidelines recommend 85 registered pregnant women per full-time working midwife per year (3), however the mean number was 92.5 pregnant women per full-time position in 2013 (4).

Midwives are the primary providers of health care during pregnancy, independently responsible for surveillance of uncomplicated pregnancies and responsible for referring obstetric assessment by obstetricians when pregnancy complications or other deviations occur. Additionally, ANC midwives are responsible for parental support, family planning, and prescription of contraceptives, as well as for performing the national population-based screening for cervical cancer. As part of their ANC assignments, midwives manage different patient-related administrative systems (3). Their administrative work tasks include registering data in the Swedish Pregnancy Register (SPR), a national quality register containing individual data on pregnancies, deliveries, and prenatal diagnosis procedures, as well as data on organisation and local clinical guidelines. All users of the register have access to outcome data via an on-line report system (2). Previously, all variables were registered manually by ANC midwives, but since 2015 a majority of the variables are transferred electronically from the digital medical records to the SPR (personal message). The mean age of ANC midwives was 51.1 in 2012 (median 53 years), and the mean length of work experience was 21.4 years (2).

Work conditions

In Sweden and the Netherlands, midwives in primary health care are generally content with their work situation (5, 6). Swedish and Norwegian midwives working in primary health care are more satisfied than hospital-based midwives (5, 7). In the Netherlands, primary health care midwives value supportive co-operation and teamwork as important factors for job satisfaction (6). Autonomy is a primary predictor of work satisfaction among nurses and midwives in Sweden, the Netherlands, and USA (5, 6, 8).

Europe has been exposed to extensive immigration during the last years. During 2013, 54,259 people sought asylum in Sweden, compared to 162,877 in 2015. Of those who applied for asylum in 2015, 24,097 were women of fertile age, defined as 18-44 years of age (9). According to Swedish law, all pregnant women and children have equal right to free health care (10).

Prenatal diagnosis

Early prenatal diagnosis in Sweden includes a routine ultrasound examination at 17 to 20 weeks of gestation. In addition, combined ultrasound and blood test (CUB), chorionic villus sampling (CVS), and amniocentesis (AC) are also available (11). However, the prenatal diagnosis methods offered vary between counties in Sweden (4, 12). ANC are by law obliged to offer expecting parents information on prenatal diagnosis (13). This information is intended to help expecting parents make an informed choice. The information should include ethical aspects and be tailored to the expecting parents' individual needs and voluntariness should be emphasised. The expectant parents should also be given time to make a decision; that is, they shouldn't be required to make a decision immediately after receiving this information (13). A Swedish study concludes that information should be provided during a separate visit and presented by a specially-trained midwife (14). It has been suggested that if information is provided audio-visually through a video, parents will make an informed choice to a higher degree (15). To inform on prenatal diagnosis with confidence, additional education on the subject has been requested by Swedish midwives (16, 17).

AIMS

This study investigates the current work situation for midwives working at antenatal care clinics. The specific aims are *i)* to explore straining and supporting factors affecting the work situation *ii)* explore midwives' experiences on provision of information on prenatal diagnosis to expecting parents.

METHODS

Study design

This qualitative study used data collected during semi-structured telephone interviews with each participant. The interviews were recorded digitally and transcribed.

Data analysis

Data were analysed by applying qualitative manifest and latent content analysis inspired by Graneheim and Lundman (18). The method requires a systematic analysis of the obvious content of the text and an interpretation of the text's underlying meaning (18). All interviews were closely read by the first author to gain a sense of the whole and to identify content areas. Meaning units were identified and condensed and codes were created. Codes were categorized into groups containing similar meaning and content, and categories and their subcategories were identified. These steps of analysis were performed by KP and IM. The transcripts were re-read several times to ensure that all areas of the interviews were covered by the categories. Later, all the authors collaboratively discussed and interpreted the content until consensus was reached. Finally, an overarching theme emerged during analysis.

Interview guide

An interview guide was developed by the authors based on the literature and the authors' previous research and clinical experiences. All authors had substantial experience with antenatal care as midwives (KP and MP) and as an obstetrician (IM). The interview guide included key domains and probing questions. The interview guide was pilot-tested before the data collection and no change was done. From the fourth interview, an additional question on collaboration with obstetricians/physicians in family medicine was included in the interview guide (Table 1).

Table 1. Key domains in the interview guide

The midwives´ experiences/views on:
WORK SITUATION
• Overall work situation
• Supportive factors
• Straining factors
PRENATAL DIAGNOSIS
• Informing expecting parents
• Knowledge on prenatal diagnosis in relation to demands

Recruitment of study participants and data collection

Purposive sampling was used to recruit between 12 and 15 ANC midwives working at different locations in Sweden. The aim was to recruit participants varying in age and work experience from different ANC settings, i.e., representing a variety of ANC organisations, patient volume, demography, socio-economy as well as geographical regions. The first author (KP) informed the ACC in each selected MHCA (N=11) about the purpose of the study and asked for help identifying local midwives who fulfilled the inclusion criteria. From this interaction, a list of names and e-mail addresses of eligible midwives was created. The first author e-mailed these midwives an invitation to participate in the study along with information about the study. In total, 24 midwives were contacted (including the pilot interview), and one reminder was sent to those who did not respond to the first invitation. Three declined participation and six did not reply to any of the e-mails, resulting in a total sample of 15 midwives working in 11 different MHCAs. The participants were provided oral and written information on the aims of the study and were told that their anonymity would be secured. The voluntary nature of participation and the possibility to discontinue their participation at any time was emphasised. A signed informed consent was obtained from each participant before the study.

After 14 interviews, saturation of data was achieved. To assure saturation of data, a 15th interview was conducted; however, this extra interview revealed no further significant information. Before each interview, baseline information was collected on age, work experience as a midwife (years), work experience as a midwife in antenatal care (years), other education, and the organisation of their ANC (private/public). Data were collected from February 2015 to February 2016. The interviews were conducted at a time chosen by the interviewees and lasted 37 to 55 minutes with a mean time of 44 minutes. The participants were 34 to 62 years of age (mean age 51.4) and reported work experience as midwives in antenatal care was between four and 27 years with a mean time of 12.6 years. All participants were females. Three participants had, apart from midwifery, other specialist diplomas in nursing, and two participants held other university degrees. Two of the participants were heads of their respective ANC. Characteristics of participants are presented in Table 2. The Regional Ethical Board at Umeå University (Umeå, Sweden) approved the study (Dno 2012-44-31M).

Table 2. Characteristics of participants

Participant	Age (years)	Work experience in antenatal care (years)	Public/Private health care
1 (pilot)	61	24	Private health care
2	57	14	Public health care
3	48	9	Public health care
4	39	4	Public health care
5	43	7	Public health care
6	47	4	Private health care
7	56	16	Private health care
8	57	14	Private health care
9	61	12	Private health care
10	45	3.5	Public health care
11	51	17	Private health care
12	62	23	Public health care
13	58	10	Public health care
14	52	27	Public health care
15	34	4	Public health care

FINDINGS

The overall emerging theme "Responsibility is rewarding and demanding" describes the participants' satisfaction with their work situation, although it was considered demanding in several aspects. Well-defined structures regulating work and valuable collaboration in the chain of health care for pregnant women were supportive factors. The administrative work load and some of the organisational factors out of the midwives' control were reported as aggravating work performance. Informing expecting parents about prenatal diagnosis was perceived as challenging. Themes, categories, and their sub-categories are presented in Table 3.

Table 3. Theme, categories and their sub-categories

Theme	Category	Sub-category
Bearing responsibility is rewarding and demanding	Depending on administrative tools and supportive professionals	Administrative work is a necessity although strenuous Assistants can facilitate the work Head's understanding facilitates the mission
	Developing as a health professional	Developing self-knowledge and competence Alone and together at the same time The weight of continuing education Autonomy is essential for work satisfaction Rewarding moments in daily work
	Coping with responsibility and demanding work tasks	Economic responsibility disseminated to the individual midwife Being disrupted during encounters is stressful Being available for the patient Immigrant status increases the demands in antenatal care Coping with changing work load exposure
	Operating in the chain of care	Functions underpinning the work Referring to higher level of health care
	Counselling on prenatal diagnosis – a mission like no other	Counselling on prenatal diagnosis is challenging Emerging ethical dilemmas for all involved Is this really my work task?

Depending on administrative tools and supportive professionals

This category includes three sub-categories: "Administrative work is a necessity although strenuous", "Assistants can facilitate the work", and "Head's understanding facilitates the mission". All three sub-categories describe structures affecting how midwives conduct their work tasks.

Administrative work is a necessity, although strenuous

The participants acknowledged the necessity of patient-related administrative work tasks although these tasks were perceived as strenuous and time consuming in relation to the time allocated to interact with patients. Some participants noted that the use of the electronic logbook was very time consuming and inefficient. Concerns over safety and quality of patient data when using several IT-systems were also raised. Some participants regarded the administrative work as a natural part of the encounter with the patient and nothing they had to pay special attention to. The recently launched SPR web-application (2015) was described as easy to use because few variables had to be registered manually. The two ANC heads reported SPR as a useful tool as it allowed them to compare their own ANC outcomes with other ANC outcomes.

> …*I feel like the computer takes lots of time… steals time from my patients because I have to look at the screen, we have to book appointments, I have to look at the journal*…. (Participant no. 3)

> *I work fairly fast and effectively… and am always working simultaneously when meeting with the patient. It isn't like I stare at the screen all the time but I do things like tick boxes and fill in the year and I can fill in these things when the patient is present.* (Participant no. 2)

Assistants can facilitate the work

Not having an assistant to help with administrative work tasks added stress to the midwives' work situation. A significant part of their current work tasks did not require the skills of a midwife. These tasks included ordering supplies, performing receptionist work tasks, and cleaning rooms.

Head's understanding facilitates the mission

A head that understood the content and nature of antenatal care and who was easy to get in touch with was appreciated as significantly supportive. Participants reported difficulties with heads who did not understand the character of midwifery or had limited knowledge about ANC.

> *[To be] well acquainted with our action plans and our mission… and you don't have to be a midwife for that… you can do if you are an interested manager.* (Participant no 12)

Developing as a health professional

This category contains the following sub-categories: "Developing self-knowledge and competence", "Being alone and together at the same time", "The weight of continuing education", and "Autonomy is essential for work satisfaction". The sub-categories echo the participants' experiences with factors that enhance their professional role.

Developing self-knowledge and competence

The midwives valued counselling related to their encounters with patients. Some participants expressed a need for reflection about their own emotional reactions towards patients, and some participants stressed the importance of having close collaboration with other health care providers such as psychiatric health care.

> *…it could be something like, why do I get so irritated at this person [the pregnant woman], she hasn't done anything to me, but there is something that irritates me… How should I act to be a good midwife so I can still interact with her… because we are different people and such, and this helps us do a better job ourselves.* (Participant no 5)

Being alone and together at the same time

Working as an ANC midwife was perceived as a solitary mission. It was expressed, both by midwives working alone and by those having several colleagues, as a feeling of bearing the total responsibility for the pregnant woman. Key factors for job satisfaction were getting along with their colleagues and having confidence in their colleagues' competence as well as an atmosphere that encouraged midwives to seek advice from one another.

The weight of continuing education

Continuing education was considered necessary as it allowed the midwives to stay up-to-date with advances in ANC and new clinical guidelines in the field of reproductive health. The importance of evidence-based health care was emphasised and continuing education was seen as providing the tools needed to improve their health care services.

> *…as soon as there has been some training, you think about what we should do, we have to change, we sit isolated in our rooms… we have to meet [and] discuss so that we make the right decisions when we are on our own.* (Participant no 5)

Autonomy is essential for work satisfaction

The opportunity to individually plan work hours was reported as very satisfactory. To be experienced in ANC was a prerequisite to comprehending the significance on how the number of antenatal booking interviews during one week affected the workload many months later. That is, extensive experience gave a sense of being in control of the work tasks and the work situation.

> *…it is easy to get too caught up in the pace… having very many patients, but I try to also think about providing good quality and stay at a level that is manageable.* (Participant no 1)

> *…you know, when you are 61… I don't need to run home and make dinner for anyone… Now that I'm in my golden years, I just need to deliver, you could say after 30 years.* (Participant no. 9)

Rewarding moments in daily work

The work was considered as a source of joy in itself. Encounters with women through their entire fertile age were one of the rewarding aspects. It was considered personally gratifying to follow a young person grow up and mature in life and was perceived as a token of appreciation if a woman chose to contact the same midwife during subsequent pregnancies. Participants working in smaller communities noted that it was satisfying getting to know families well and being a known in the community for their service. This recognition, however, required integrity when meeting patients outside their professional sphere.

> *…I love it. I think it is lots of fun… the most fun is following the pregnant women so that you get to know them a bit.* (Participant no. 10)

> *…sometimes ... you meet women who you become incredibly worried about since you think it is never going to work… and then it does anyway… many who you see at the youth clinic and think they will never grow up… and now they are completely*

established in society and are doing well… that's given me a lot… a belief in having children… you grow from it. (Participant no. 12)

Coping with responsibility and demanding work tasks

The category includes the sub-categories "Economic responsibility disseminated to the individual midwife", "Being disrupted during encounters is stressful", "Being available for the patient", "Coping with changing work load exposure", and "Immigrant status increases the demands in antenatal care". All five sub-categories imply stressful factors influencing the work situation.

Economic responsibility disseminated to the individual midwife

Participants working in counties with performance-based funding of health care reported that economic aspects were permanently on the agenda and therefore constantly kept in mind, which was perceived as burdensome and stressful. Participants in other counties, however, reported that funding was not an issue that affected their daily work.

Being disrupted during encounters is stressful

Unscheduled visits by pregnant women to the ANC could be stressful. Every unscheduled visit required immediate assessment of the urgency of the matter. That is, these unscheduled visits required assessing whether the patient required immediate attention.

Being available for the patient

There was a demand on availability regarding opening hours, telephone hours, and e-mail contact. Being constantly available for the patients was perceived as double-edged; on one hand this access was an obvious benefit for the patient, but on the other hand it created a stressful work situation for the midwife. Extensive telephone hours and constant checking of e-mails meant time was deducted from meeting with other patients.

Coping with changing work load

Although commonly perceived as manageable, an overall high work load was reported. Pregnant women were prioritized before other patient categories. Working alone or with only one colleague could be seen as stressful, especially in relation to absence from work as no other midwife could take over the work tasks. To be loyal to colleagues and patients was considered important.

…but it is also a feeling that I don't do what I should… that I should take a holiday … that I am letting my colleagues down. (Participant no. 12)

Immigrant status increases the demands in antenatal care

The increased number of asylum-seeking women was perceived as a challenge. A shortage of skilled interpreters was a common experience. Not being sure of the quality of interpretation caused an uncertainty in the communication with the patient. Regional detention centres situated in remote areas implied practical issues that had to be taken into account when planning visits, complicating ANC surveillance. However, meeting women from other cultures was also described as enriching.

Operating in the chain of care

This category includes two sub-categories "Functions underpinning the work" and "Referring to higher level of competence". These sub-categories describe structures supporting the chain of health care professionals surveying pregnant women, i.e., midwives and general practitioners in primary health care as well as obstetricians in hospital-based health care.

Functions underpinning the work

Internet-based local clinical guidelines for ANC were regarded as highly valuable for daily work and considered as important tools for providing evidence-based health care. The ACO and the ACC were seen as essential in ensuring the assignments and quality improvements in ANC.

> *I think memos and guidelines are actually really good …, because … we are supposed to work based on, what do you say … science and proven experience.* (Participant no. 7)

> *…they are the ones [ACO and ACC] who are responsible for our continuing education and updating the care programme and … yes, it works well. They are very enthusiastic.* (Participant no. 14)

Referring to higher level of health care

The possibility to refer pregnant women to the hospital (i.e., a higher level of health care) was considered important. Overall, collaboration with hospitals was very valuable. Midwives in remote geographical areas could sometimes hesitate on whether the pregnant woman needed to be assessed by a physician, since the travel to the hospital could take several hours.

Informing on prenatal diagnosis – a mission like no other

This category comprises three sub-categories: "Counselling on prenatal diagnosis is challenging", "Emerging ethical dilemmas for all involved", and "Is this really my work task?". The sub-categories reflect different aspects of the challenges midwives experience when informing expecting parents about prenatal diagnosis without allowing their own opinions to affect the information. This neutral expression of information was intended to help expecting parents make informed as well as autonomous decisions about their care.

Counselling on prenatal diagnosis is challenging

In general, midwives considered their knowledge on prenatal diagnosis as sufficient for informing expecting parents. However, providing information about the CUB and the associated risk assessments were perceived as difficult. Particular challenges occurred when informing either highly educated expecting parents or parents with no or very limited pre-understanding of prenatal diagnosis. Highly educated expecting parents sometimes asked questions that could uncover a midwife's insufficient knowledge. Informing expecting parents with no or limited pre-understanding of prenatal diagnosis was recognised as requiring special skills.

> …*It's an important aspect [providing information about prenatal diagnosis]...because it easily happens, if you talk a lot with people who don't really understand what it's all about, that you end up with fewer and fewer words to explain it.* (Participant no. 5)

Emerging ethical dilemmas for all involved

Some participants reported having no difficulties providing information about prenatal diagnosis, an attitude expressed as "what is right for the expecting parents is right for me". Other participants questioned the increased focus on prenatal diagnosis by the health care system as well as by expecting parents. Prenatal diagnosis was perceived as ethically difficult to comprehend. A concern was raised on how the fundamental value "all human beings are equal in dignity and rights" could agree with methods aimed to detect Down's syndrome. Another concern discussed was the inequality regarding offers on prenatal diagnosis in different counties as well as the unequal request of prenatal diagnosis by highly educated expecting parents compared to expecting parents with a lower educational level.

> *…at its most extreme, it can mean that we don't have any children with Down's syndrome… and that is really strange for me to also do what we do… I mean equality regardless of what functionality you have.* (Participant no. 12)

Is this really my work task?

As information on prenatal diagnosis is a general offer, some participants considered that all ANC midwives should provide this information. Others believed that it was better if this information task were performed by health professionals specialised in prenatal diagnosis.

DISCUSSION

The main positive findings in this study were the midwives enjoyed working in an ANC, appreciated well-defined organisational structures, and the collaboration with other health professionals in the chain of care for pregnant women. To improve their work situation, midwives wanted to reduce the administrative work load and to receive support from assistants. Prenatal diagnosis was perceived as ethically difficult and informing expectant parents was seen as challenging. The Theory of Organisational Empowerment includes six conditions required for empowerment to take place. The findings in our study respond to some of these, e.g., access to information, access to support, and access to resources.

The midwives highly appreciated the clinical guidelines to provide evidence-based health care This finding agrees with previous studies reporting the importance of relevant framework to support midwives' and nurses' practice through national policies, regulations, and guidelines (19). To deal with constant innovation, midwifery practice includes the challenge of maintaining competence and receiving up-dated knowledge (19). Regular briefings and shared clinical decision-making are addressed as key facilitators in primary health care (20). The collaboration between the professional organisations for obstetricians and midwives in creating national guidelines is supportive, and Swedish midwives are in general satisfied with the relation between midwives and obstetricians (5). In our study, a supportive and collegial atmosphere and confidence in colleagues and other professionals involved in patient care were emphasised as assuring the quality of the midwives' practice and a major component in work satisfaction. Continuing education, counselling addressing emotional reactions towards patients, as well as counselling on medical issues were experienced as enabling factors for improving clinical work.

The different ANC assignments in Sweden including encounters with women of different ages was described as rewarding and contributing to work satisfaction, findings that are in line with previous studies (6, 8, 19). In Sweden, ANC midwives schedule appointments, which increases the sense of control

and flexibility (5). Our study's findings agree with previous studies' findings that the possibility to regulate one's own work hours as well as to schedule one's own work day contributed to the midwives' work satisfaction. Some participants stressed long work experience as very valuable and contributed to work satisfaction. The administrative work tasks were specifically pointed out as a demanding and time consuming. A reduction of work tasks not requiring the skills of a midwife was desired, and it was suggested that an assistant could do this work. Our findings agree with previous reports on midwives' desire to reduce non-client related activities to improve their work situation (6). Informing expecting parents on prenatal diagnosis was perceived as challenging the participants' ability to explain complex matters, their level of knowledge, and their personal values. Similar issues have been raised by Australian General Practitioners (21).

METHODOLOGICAL CONSIDERATIONS

Purposive sampling was applied to capture a variety of perspectives and experiences from participants from different settings in order to increase credibility of the study. Data collection through individual telephone interviews were conducted, so non-verbal information might have been lost (22). A similar study found that telephone interviews were an effective data collection method (23). Time and cost efficiency (24) as well the flexibility for participants to choose the interview time were considered when choosing a method. Consistency in data collection and analysis were secured using a semi-structured interview guide used for all interviews, including key domains and open-ended questions. Furthermore, the first author (KP) performed all interviews over 12 months, a strategy that increased dependability. To ensure transferability, data were collected until saturation was achieved. Confirmability was sought by discussing the results within the research team, all experienced in ANC but from different professional perspectives, challenging their pre-understanding. A possible limitation is that the eligible participants were chosen by the ACC, so it cannot be excluded that eligible participants were chosen by some other criteria. Another potential limitation was that first author (KP) was engaged in the SPR, which might have biased the participants when expressing opinions about SPR. Finally, significant aspects of ANC might have been overlooked in the interviews.

CONCLUSIONS

Midwives enjoyed their work in antenatal care. They appreciated the collaboration between professionals in the chain of health care for pregnant women. Medical guidelines and continuing education are considered essential in providing good quality and evidence-based health care. The administrative

work was strenuous, but some of these tasks can be performed by others. Inter-operability between different IT-systems could decrease the work load. Prenatal diagnosis is an ethically complex issue, sometimes in conflict with personal values. Moreover, informing patients about prenatal diagnosis can be challenging. The development of new pedagogical tools may help midwives provide intelligible information to expecting parents with varying pre-understandings about prenatal diagnosis.

COMPETEING INTERESTS

The authors declare that they have no competing interests.

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APPENDIX Interview guide, Study IV (in English)

Table 1. Key domains in the interview guide

The midwives´ experiences/views on:

WORK SITUATION
- Overall work situation
- Supportive factors
- Straining factors

PRENATAL DIAGNOSIS
- Informing expecting parents
- Knowledge on prenatal diagnosis in relation to demands